Living with the label of Dyslexia

by

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DECLARATION

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21 October 2019

SIGNATURE DATE

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Always believe in the impossible! And never, ever give up! (Archibald, 2016).

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DEDICATION

"I can do all things through Christ who strengthens me"

(Philippians 4:13)

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To my children - may this inspire you to never give up no matter what challenges may come your way, and to always believe that your dreams and goals can be attained if you work hard and strive towards them. Always be mindful of Albert Einstein's wise words, "Never give up on what you really want to do. The person with big dreams is more powerful than one with all the facts". Michael Phelps stated that "You can't put a limit on anything. The more you dream, the farther you get."

Achieving this degree is proof of this. My impossible dream became possible.

ABSTRACT

Included in the challenges possibly faced by those with dyslexia, is the acquisition of literacy skills. Despite 21st century advancements made in technology, literacy skills remain central to education and day-to-day living. Therefore, it is essential to meet the learning needs of those with dyslexia, as failure herein could impact negatively on their lived experiences and on the attainment of their needs.

The main aim of this transcendental phenomenological study was to explore, and describe the first-hand lifelong experiences of adults living with dyslexia. The study utilised the theoretical and conceptual frameworks of Bronfenbrenner's Ecological Systems Theory and Maslow's Hierarchy of Needs. Following a multistage procedure, a criterion-based sampling strategy was used to select study participants, comprising of eight South African adults between the ages of 18 and 40, who were formally diagnosed with dyslexia. Data collection included semi-structured one-on-one in-depth interviews and the researcher's reflective journal.

Data analysis, following the principles of phenomenology, resulted in the formation of five themes. Findings reveal that dyslexia is viewed positively by adults diagnosed with it, and used as a driving force to succeed and obtain set goals. Various professionals were consulted with the aim of obtaining a diagnosis; however, obtaining a diagnosis and hence an explanation for their learning challenges, was a stressful experience for both the participants and their parents. Families provide much assistance with school work, although all participants revealed negative schooling experiences caused by schools not acknowledging dyslexia and not meeting their specific learning needs. Although living with dyslexia presents challenges, coping mechanisms are in place for overcoming anticipated challenges. Whilst self-confidence is not negatively affected, dyslexia appears to negatively affect the self-esteem of some. This study found that the dyslexia label is preferred to that of having additional learning needs, as the dyslexia label is viewed as referring to specific challenges and not to entire learning abilities. Finally, this study hopes to provide a deeper understanding of the experiences of those living with dyslexia and fill the existing gap in South African literature.

KEY TERMS:

Dyslexia; learning disabilities; labelling; Maslow's Hierarchy of Needs; Bronfenbrenner's Ecological Systems Theory; phenomenology:

ABBREVIATIONS AND ACRONYMNS

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactive Disorder
CV	Curriculum vitae
DBE	Department of Basic Education
DHET	Department of Higher Education and Training
DoE	Department of Education
DSM	Diagnostic and Statistical Manual of Mental Disorders
EST	Ecological Systems Theory
EWP6	Education White Paper 6
GET	General Education and Training
HPCSA	Health Professions Council of South Africa
IDA	International Dyslexia Association
IEB	Independent Examinations Board
LD	Learning Disabilities
LSEN	Learners with Special Education Needs
NSC	National Senior Certificate
SA	South Africa
SASA	South African Schools Act
SEN	Special Education Needs
SIAS	Policy on Screening, Identification, Assessment and Support
SKYPE	Computer Assisted Personal Interviewing
SLD	Specific Learning Disorder
SLI	Specific Language Impairment
SSRC	Special Schools as Resource Centres

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I'm asked to read aloud in front of the class,
But the words swim before my eyes.
I start to sweat, I'm breathing fast;
The print I see I cannot recognize.

The students stare expectantly, they wait for me to speak.
But I can't focus, can't grasp the words;
I feel so useless, I feel so weak;
My eyes tear up, and my vision's blurred.

The giggles start as they see my trouble,
No one seems to understand what's wrong.
The letters, for me, flip around and double;
My class assumes I'm stupid because I'm taking so long.

Their laughing faces fill my head,
Mocking me, making me feel like I'm somehow less
Important than they. "Let one of us read instead!"
I shrink at their success.

I don't know why I am this way,
I've done nothing to deserve this;
Why choose one person through which to convey
The pressure that becomes paralysis?

I finally decide there's no more use;
I descend from the podium, shamefaced.
My teacher's mad, she thinks it's some ruse;
For my punishment, I am braced.

I sink in my seat, my skin a lot paler,
Through the window, a cloud covers the sun.
But I don't notice, all I see is my failure;
Once again, the dyslexia has won.

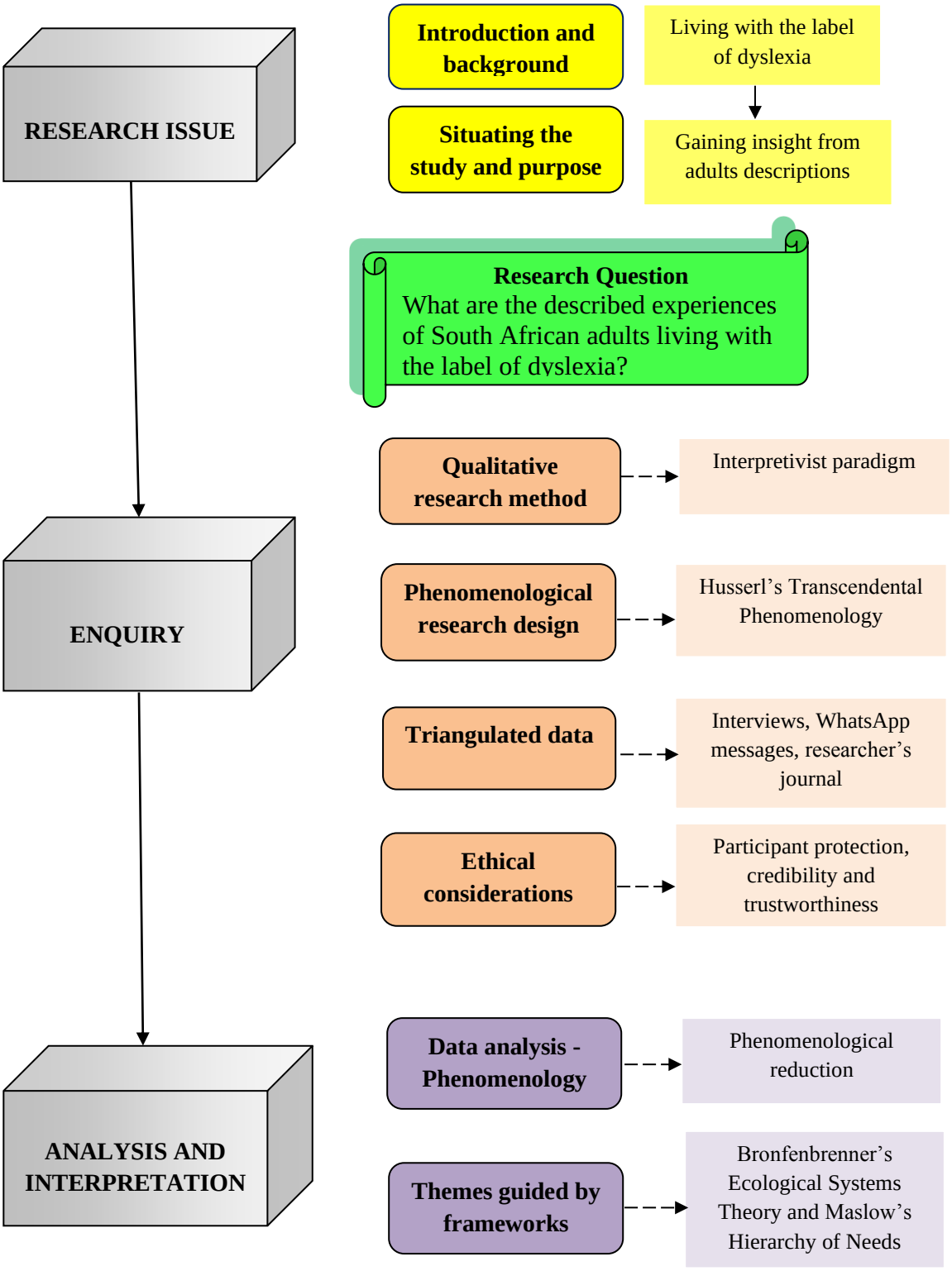
How dyslexia makes me feel.

Tilly, a Grade 9 Canadian learner (Canadian Dyslexia Association, n.d.)

CHAPTER 1

INTRODUCTION AND BACKGROUND

OVERVIEW OF THE CHAPTER



1.1 INTRODUCTION

In the 21st century, literacy remains the foundation for most facets of education and daily living. The three Rs (Reading, wRiting and aRithmetic) are the first skills taught daily from the commencement of formal education, and are stated as being the foundation of education. Most educational qualifications are mainly gained through examinations that require the skill of reading and writing. Despite the modern world being largely influenced and aided by technology, the ability to read, write and count remains central to human existence by assisting people to make sense of and understand the world. Daily, people are confronted with situations both in and out of the home, school and the workplace that require the skill of literacy and counting. Whilst many find these skills fairly easy to learn and something that occurs without thought, almost habitual; however, there are many who find it a challenge, which Shaywitz and Shaywitz (2013) states appears to be unimaginable for those who see it as effortless. Challenges in reading, writing, spelling and mathematics are identified as falling under the umbrella of a learning disability commonly referred to as dyslexia[1].

Dyslexia is regarded as the most common learning disability that ranges from mild to severe and differs from individual to individual. It is viewed as a neurobiological disorder that is genetic and therefore hereditary (Allen, 2010; Van der Leij, 2013). Dyslexia is found in both children and adults, is never outgrown; however, many with dyslexia have achieved success both in school as well as in the workplace. The International Dyslexia Association (IDA) states that as many as 15-20% of the world's population have some of the symptoms of dyslexia and whilst they struggle with academic learning, they are able to benefit from instruction suited for them (IDA, 2016). In South Africa (SA), one in ten persons has dyslexia and this equates to approximately 5 million South Africans who encounter literacy challenges in school, as well as in the workplace (Pienaar, 2013). The Red Apple Dyslexia Association (2017) states that approximately 15% of South Africans, regardless of culture, language, age and gender, have dyslexia.

[1] Dyslexia is a learning difficulty that affects the skills needed for accurate and fluent word reading and spelling (Rose, 2009).

1.2 BACKGROUND TO THE STUDY

Despite the acknowledgement of dyslexia as evidenced in the founding and existence of various dyslexia associations and teaching centres worldwide, including SA, the existence of dyslexia, as well as a universally accepted definition for dyslexia, remains shrouded in controversy and debate. This is evident in Africa where the effects of not having a clear definition is seen as impeding the identification and diagnoses of such learners, thus negatively affecting the education and the assistance given to them (Pienaar, 2013). The controversy that surrounds many aspects of dyslexia impacts greatly on the use of the label of dyslexia. This despite the fact that since the 1990s, as a result of copious research into dyslexia, it has moved from being a hidden disability to one that is acknowledged in academic, intellectual and professional fields (Aladwani, & Al Shaye, 2012). An increase in knowledge and awareness of dyslexia has led to the question of whether people, who have been formally diagnosed with dyslexia[2], should be labelled as such. My experiences as a teacher and as a master's student has revealed that professionals, including teachers, authors and researchers have mixed feelings about diagnoses and the use of this label, with many viewing it negatively. The Davis Dyslexia Association International (2014) states that such views and feelings exist, despite the fact that many with dyslexia proudly embrace their diagnosis, and hence the label.

Research conducted thus far into the use of a label for those with learning disabilities, the umbrella term under which dyslexia falls, as well as into the experiences of adults living with such a label, has been explored internationally, by researchers mainly in the United States of America (USA) (Banks, 2017; Gold & Richards, 2012; Higgins, Raskind, McCloskey, 2011; Zembylas & Isenbarger, 2002), in Canada (DeRoche, 2015) and in the United Kingdom (Gibbs & Elliott, 2015; Hatton, 2009; Macdonald, 2013; Scior, Connolly, & Willaims, 2013). Whilst worldwide research into labelling is increasing, few have the labelled persons as participants, and thereby have gained insight into their views. My endeavours thus far to find SA research describing the experiences of adults living with the label of dyslexia, or even SA research that has adults with dyslexia as participants, have been unsuccessful, therefore no such research to date has been located. It is this gap which this study intended to fill, with the aim of possibly gaining a deeper understanding of the label of dyslexia, as told by SA adults diagnosed with dyslexia.

[2] In SA, a formal diagnosis of dyslexia is made by an educational psychologist or by approved professionals, registered with the Health Professions Council of South Africa (HPCSA).

This study provides direct research into these experiences whereby it affords those with dyslexia the opportunity to express their views and feelings and not to have others speak about it on their behalf. The researcher herein is of the view that decisions and choices made for those with the label of dyslexia, should be based on the views and feelings of those experiencing it first-hand and should not be made for them by others. Whilst acknowledging that the labelling of persons with learning challenges is a controversial and delicate topic, this study, using the question asked by Boyle (2014, p.213) "What's in a name?" and acknowledging like Boyle that it cannot be simply answered with a yes or a no, seeks to gain an in-depth view into the use and worth of the label by using the experiences described by SA adults who are living with this label and hence personally experiencing life with it.

1.3 RATIONALE FOR THE STUDY

The selection of the topic for this study is consistent with the views of Rubin and Rubin (2012) who state that topics selected in a study are usually borne from personal experiences or frustrations. My motivation for undertaking this research, which primarily describes the experiences and views of SA adults diagnosed with dyslexia, as well as their experiences and views of the label, was founded in both my professional and personal capacities. I select the specific term 'dyslexia' following the views of Taylor (2011), that being specific is more beneficial to the person than a non-specific label such as Special Education Needs (SEN). My interest in both dyslexia and labelling stems from four different areas of my life, namely, as a learner, a primary school teacher with 19 years' experience, a researcher (master's student) and as a mother.

To understand the environments of two aspects of my rationale, namely as a learner and as a primary school teacher, it is important to give some personal background information on myself and the education system in which I was placed as a learner and teacher. This placement was enforced through the nationalist Government in South Africa enacting laws that defined and enforced segregation through laws such as the Prohibition of Mixed Marriages Act, Act No 55 of 1949, Population Registration Act, Act No 30 of 1950 and the Group Areas Act, Act No 41 of 1950 (Gandhi-Luthuli Documentation Centre, 2003). It was therefore in an apartheid segregated education system that I encountered dyslexia as a learner in Standard 5 (Grade 7), and then as a teacher in pre-democracy (1994) years. During this era, all persons in SA were placed in one of the four race groups based on their racial identity, namely White, Coloured, Indian and Black and could only be educated by schools that fell under the controlling body

for each race group; however private schools were open to educating learners from all race groups. I attended a school for 'Coloureds' (race group in SA) that fell under the House of Representatives (education department) which was based in Cape Town and from where all Coloured schools in SA were controlled. The monetary allocation given to the four education departments differed with White Education receiving far more than the other three departments and Bantu Education receiving the least (further discussed in Chapter 2). This not only resulted in inferior education but also in higher teacher-learner ratios in Coloured, Indian and Bantu schools, with Bantu Education having the highest teacher learner ratio. In Pietermaritzburg, where I grew up and was educated, specialist schools within my education system did not exist.

It was within this inferior education system, whilst in Standard 5 (Grade 7), that I became aware of the challenges faced by two of my peers who found literacy a challenge. One was a female and the other a male, who I will refer to as Alice and Paul. With many learners in a class (40 and above) Alice and Paul received no assistance for the challenges that they encountered. Acknowledgement can be given to our teachers, who did not embarrass them by dwelling on their literacy failures, but they were, however, ignored. My adult view is that our teachers saw them as being unteachable, did not know how to teach them and as learners who did not belong in mainstream classes. However, mainstream schools that existed for Coloured learners in Pietermaritzburg were limited with one junior primary school (Grades 1-3), one senior primary school (Grades 4-6) and one high school (Grades 7-12).

Alice was my friend and I used to feel sad for her. No matter how hard she tried, she could not read and write and as a learner I found this confusing. For me, reading and writing were not difficult, and I could not understand her challenges. Paul on the other hand confused me even more. Whilst reading, writing and spelling posed a huge challenge for him, he loved mathematics and unlike us 'normal'[3] learners, he was always able to provide the correct solutions. However, if it was a story sum (a sum with written words) then he did not bother to attempt it. This was also found in a case study conducted in Meier-Hedde (2011) where a 12-year old was unable to find the solutions for story sums unless the sum was read to him, but once this occurred, he was able to provide the solutions without further assistance. Sadly, both learners were promoted year after year and eventually at the end of Standard 7 (Grade 9), Alice left school and Paul left at the end of Standard 8 (Grade 10). On meeting him as an adult, Paul

[3] 'normal' learners was my immature view as a learner.

indicated that whilst a learner, he had been formally diagnosed as having dyslexia by an educational psychologist. However, as a result of educators not knowing how to assist him in overcoming his challenges, he had left school to work in the family business.

Paul's educator experiences is still experienced by many, as indicated by the IDA, who state that many educators in public schools are not knowledgeable about dyslexia (IDA, 2019). Alice's learning challenge was never diagnosed because of her family's inability to pay for a diagnosis. Her belief in being diagnosed as having dyslexia is based on her son's diagnosis of dyslexia and the realisation that her challenges are very similar to those of her sons. She has since been taught to read using the methods employed for teaching reading to those with dyslexia. Alice and Paul's experiences of diagnosis concur with an Italian study conducted by Barbiero et al. (2012) to evaluate the prevalence of dyslexia in schools. This study confirmed that two out of every three learners with dyslexia had not been formally diagnosed, thus indicating that the lack of diagnoses of dyslexia is also experienced in other countries as well and not only confined to SA.

Many years later, as a teacher, my confusion and interest in getting to know more about learners who found reading and writing a challenge grew. During my 19 years as a teacher, I was faced with learners who were similar to both Alice and Paul. No matter how hard I tried to teach such learners to read and write, I failed at getting them to accomplish this. Sadly, my teacher training did not equip me with the knowledge or skills of how to assist the learner acquire these basic skills. Camp and Aldridge (2007) provide another reason for my lack of knowledge herein, in that they state that the term 'dyslexia' diminished in the 1980s and it was only in 1995 that resurgence in research and reference to it reoccurred. As a Grade 2 teacher with 47 learners in the class, I also did what my teachers had done. I stopped attempting to teach them what they could not do and tried to focus on their strengths, but as a perfectionist, it troubled me greatly. It was only during my honour's degree studies in 2011, which included the study of learning disabilities, I realised that there was a name for the literacy challenges that some faced and that teaching them to accomplish this was possible. As a qualified teacher, I had lacked this knowledge and I am left with feelings of guilt in that I did not understand the needs of these learners nor was I equipped to address them. This resulted in my interest in dyslexia which later included the labelling of those with dyslexia. My pre-study view is that such a label could make them known to the school and to others as it is an indication of their challenges and

thereby places them in a group with others who experience the same challenges or characteristics.

As a master's student, I visited a special school in search of learners whom I could use as my study participants and interview, so as to gain insight into the subject matter that I was exploring in my dissertation. The head of the school was helpful, but on hearing that the University of South Africa (Unisa) Ethics Committee had indicated that my study participants had to be formally diagnosed learners with dyslexia, her response was "good God these learners do not have to be burdened with another label." Based on my views founded as the mother of a child with a learning disability, I was taken aback and have since reflected and questioned this view many times. The headmistress was of the view that the learners, attending a special school, carried a label and that was sufficient. I felt confused and my preliminary investigations led me to realise that labels regarding learning disabilities are sometimes shied away from, resulting in a reluctance to use them. My experience is verified by Groth (n.d.) and in the various international case studies explored in Anderson and Meier-Hedde (2011) which revealed that often some parents and teachers are reluctant to use the word 'dyslexia' or 'dyslexic', even if the child is enrolled in a dyslexia tutoring or assistance programme. Bishop (2014) concurs and refers to the resistance shown in educational institutions to giving learners diagnostic labels.

My endeavours to find research participants for my master's dissertation also led me to a local tutoring centre which advertises in the media that they assist learners with dyslexia to overcome their reading problems. The word "dyslexia" always comes before "reading problems" in their advertisements. Surprisingly, they indicated in emails to me that they had declined to assist because that they do not endorse the label 'dyslexia' as they feel that it has negative connotations. This view concurs with Algraigray and Boyle (2017) who state that labels per se devalue people and result in society devaluing them. They further indicated that with me wanting to describe the school experiences of learners with dyslexia, I was enforcing the negative notion that dyslexia was a disability, whilst they viewed it as an inability. Alexander-Passe (2015b) rejects this view by stating that the negativity surrounding dyslexia will only be reduced if there is more awareness and knowledge from all, including society. Hence my failure to understand the views of the tutoring centre, led me to query whether we, as teachers, are assisting or not assisting such learners and persons by making decisions for them. Are we, as secondary persons, making choices for those with dyslexia and are these choices based on the

dyslexic person's views and feelings? This question is answered in the affirmative by Ingesson (2007). In my attempt to gain insight into the first-hand experiences of those with dyslexia, my desire to undertake this study was borne. This desire was further fuelled by my experiences faced as a parent.

My 30-year-old daughter was diagnosed at the age of six with Attention Deficit Disorder (ADD). Prior to diagnosis and the assistance she received, I had an unhappy and frustrated child struggling with her work at school. The diagnosis, the label and the assistance that resulted, changed her from an unhappy little girl into a happy learner and child who was able to achieve. With the help of her parents, she felt no different to her peers. My daughter never shies away from her label, uses her medication when needed and has achieved a matriculation certificate with an A symbol in four subjects. She has a Bachelor of Commerce degree in Information Technology majoring in Computers and Accountancy. As a result of her diagnosis and label, she knew that her majors in her degree would have to be practical subjects and not theory-based subjects. Her education and occupation choices concur with the findings of Ingesson (2007), who validates that those with learning challenges make scholastic subject and occupation choices based on strengths and weaknesses, thereby utilising their coping mechanisms. Her accomplishments would never have been realised without the diagnosis and label, which has resulted in her having a better understanding of herself. I therefore have firm personal views on the power of the label of ADD, which I acknowledge are the views of a secondary person. I am however, not alone in these views as Sunderland (2014) states that by acknowledging dyslexia (in my daughter's case it was ADD), you are assisting the person to understand why they are the way that they are.

My personal view, resulting from my experience as a mother of a child with a learning challenge, is that a label is necessary to assist such learners and to help them to understand themselves. I therefore find this study to have been of great worth, both to investigate my biased view, as well as possibly assist those with dyslexia in enhancing an understanding of their needs and wants with regards to the label, as indicated by themselves and not others. Based on this personal view of labelling and my interest in dyslexia, I embarked on this study to investigate if my views of labelling, as an unlabelled person, were shared by those who live with the label of dyslexia. Acknowledging that my view in the early stage of my research was biased, as a researcher, I was aware that further reading and insight gained in my subject matter could change my present views. However, I observed the necessary steps and precautions to

ensure that my study was credible and trustworthy by carefully selecting a research design that would address any bias or presupposition. Marshall and Rossman (2016) indicate that the stating of bias by the researcher renders such bias to be more manageable and allows the reader of the final report to assess how this might or might not have affected the outcomes of the study.

1.4 DYSLEXIA

Dyslexia is a term that is widely debated with many different meanings to many people as it is complex in nature and compounded by the fact that no two individuals with dyslexia experience it in the same way (Armstrong & Squires, 2015). Dyslexia is however, commonly referred to as a learning difficulty that affects the skills needed for accurate and fluent word reading and spelling (Rose, 2009). Articulation is however, not a challenge for dyslexics (Ingesson, 2007) and they are often referred to as being articulate and intelligent (Mortimore, 2003). Dyslexia however, sometimes occurs in gifted learners resulting in a failure to recognise their challenges which impedes diagnosis (Kokot, 2005). Dyslexia therefore occurs across a range of intellectual abilities (IDA, 2016; Pienaar 2013) causing a discrepancy between intellectual ability, as opposed to their literacy challenges (Nugent, 2008). Learners with dyslexia are often misunderstood as there is a breakdown between their intelligence and reading ability (Shaywitz, 1996).

The IDA (2016) states that the main difficulties faced by dyslexics are word recognition, reading fluency, spelling and writing, learning to speak, learning letters and their sounds, organising written and spoken language, memorising number facts and hence difficulty with mathematics. Taylor, Hume and Welsh (2010) state that the challenges experienced by those identified as dyslexic differs greatly, thereby impacting on a single accepted definition for dyslexia. Various definitions can be found but the definition selected as most suited to this study, as indicated below, was adopted in 2002 by the IDA (2017a, p.1).

> *Dyslexia is characterized by difficulties with accurate and / or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge.*

Despite the controversy and denial shown towards dyslexia it is recognised as having an impact on not only the individual but also on society and the economy at large (Dyslexia International, 2016).

1.4.1 Diagnosing of Dyslexia

Diagnosing dyslexia is difficult as it has a cluster of symptoms, is multifaceted, can take many forms, varies for individuals, has similar characteristics to other learning disabilities and sometimes even overlaps with other learning disabilities (IDA, 2016; Lawrence 2009). As a result of a lack of consensus on the nature of dyslexia, consensus on diagnostic methods has not been reached. Whilst the United Kingdom (UK) and the USA have a working definition used for identification purposes, Africa does not, as yet, have this accepted working definition (Pienaar, 2013), which therefore impedes diagnosis.

Countries differ in the professionals who are consulted to make a formal diagnosis of dyslexia. In the USA, learners who portray the characteristics of dyslexia are referred to a licensed educational psychologist or to a neurologist or other medical professional qualified to provide a formal diagnosis (Davis Dyslexia Association International, 2017). The referral might be from schools, teachers or even parents who suspect that their child might have a learning challenge. In SA, a formal diagnosis of dyslexia is predominantly made by an educational psychologist or by approved professionals registered with the Health Professions Council of South Africa (HPCSA). This is a statutory body that promotes the health of South Africans, determines the standards of health professionals education and training as well as ensures that high standards of ethical and professional health practice are always maintained (HPCSA, 2018).

There is no one single test for dyslexia and various countries have their own tests or utilise the tests used in other countries. Therefore, educational psychologists and other professionals, local and international, use various assessments and tests to make a diagnosis. Whilst there is no consensus on an approved South African test or assessment to diagnose dyslexia, progress in research has resulted in an improvement in tests (Pienaar, 2013). Diagnostic assessments used by the British Dyslexia Institute are accepted by the South African Education Department for the diagnosing of dyslexia and the placement of learners in special schools. Diagnosing begins with the gathering of information gained from interviews, observations and testing collected by the learner's teacher/s, speech/language pathologist, educational assessment

specialist(s), and medical personnel (IDA, 2017b). Tests cover a range of skills and the diagnosed person is placed in different risk categories (mild, moderate and high). The value of early diagnoses and intervention is imperative as it enables the required intervention to take place, thereby providing assistance to such learners (Pirttimaa, Takala & Ladonlahti 2015; Van der Leij 2013).

1.4.2 Labelling

The use of diagnostic and hence categorical labels in special education has evoked much debate and concern. The origins of labelling are viewed by many as being founded in the medical field of disability, therefore indicating that something is medically wrong with the individual. Literature indicates that the controversy surrounding dyslexia leads to many questions and views, which ultimately impacts on the labelling of those with dyslexia. Gold and Richards (2012, p.143) affirm this in attempting to answer the question of whether labels should be used, wherein they state that "the benefits of categorically identifying and labelling students with disabilities" is a widely debated topic. However, despite this debate, thus far no SA literature on labelling has been located, thereby confirming the research gap herein. Therefore, findings on labelling discussed in this study are based on research conducted in other countries.

Various factors are found to play a role in whether labelling is acceptable or not. Culture has an important role to play in the acceptance of the labelled person, therefore the bias shown in non-accepting cultures, places a burden on the labelled individual as a result of the stigmatisation experienced and being seen as having an inadequate ability (Gold & Richards, 2012; Markham, 2005). Findings and views on labelling varies with researchers indicating the positives and negatives. Osterholm, Nash and Kritsonis (2007) and Shifrer (2016) indicate the stigma and negativity experienced by those with labels, whilst Savaria, Underwood and Sinclair, (2011) and McCloskey (2011) emphasise the importance and benefits of the labelled person's participation in the construction of the labels. As a result of the gap in academic research, and using the voice of those with dyslexia, the researcher has sought these views in the blogs of various dyslexia organisations, both local and international. The views of those diagnosed with dyslexia towards labelling reflected in such blogs, lean towards favouring the label (Redford, 2017; Sunderland, 2014). However, Wright (1991, p.469) states that the "problem of labelling will always be a problem" as it poses perplexing questions for investigation and it increases the disadvantages of negative labelling.

1.4.3 View of Adults towards Labelling

SA research, using the voice of those diagnosed with dyslexia, is scant and limited with various dyslexia associations and teaching centres providing the researcher with insight into the views and feelings of those with dyslexia towards labelling. McNulty (2003) is of the view that worldwide literature, using the voice of adults with dyslexia, is sparse thus resulting in a void in gaining insight into their emotional experiences. Research conducted in other countries reflects mixed views from individuals with dyslexia, regarding their diagnoses and living with the label. An adult dyslexic in Lesleyanne (2009) states that the diagnosis turned her life upside down, that life with the label was filled with negativity so much so that she wished she had never found out that she was dyslexic. This view is contradicted by a response from a diagnosed person in Admin (2010), wherein he stated that his parents taught him from the time of his diagnosis that dyslexia was a difference and not a challenge which resulted in the label never being a problem for him. It therefore becomes apparent that parents are in an influential position and are important role players in the way in which those with dyslexia react to their diagnoses and live with the label. An adult with dyslexia (Busby, 2013) stated that diagnosis and the label was a relief, as it provided so many answers as the diagnosis had taken her from feeling stupid, lazy and an underachiever, to feeling strong, courageous and filled with determination. She further states "I am dyslexic and proud! Without the label of dyslexia, I can guarantee my self-esteem would be zero, and I would feel stupid" (p.1).

1.4.4 Views of Parents whose Children have Dyslexia

As the result of the gap in SA literature, parental views discussed herein are not situated in the SA context and this validated the need to fill this gap and undertake this study. Gerken (2016) the director of the SA Dyslexia Association, states that some SA parents find their children's diagnoses of dyslexia an embarrassment and sometimes do not inform their children of their diagnoses. Stein (2014) states diagnosis can cause a dilemma for the parents of a child with dyslexia, as it places the parent in unknown territory and consequently, fear that labelling their child will result in the label becoming bigger than the child. Sunderland (2014), an advocate of the diagnosis and labelling of dyslexia as a result of having seven of her own children diagnosed with it, is of the view that shying away from the diagnosis is the result of the countless number of myths that surround it. Sunderland believes that a diagnosis provides the person with answers and hence a reason for the learning struggles that they face, and it further acts as a confidence booster. Murphy (2017) states that some parents do not want their children to live with the label, as they believe that their child will be disadvantaged at school and be seen as

‘dumb’, but she believes that parents are gradually starting to see the value of the label and hence changing their views.

From this discussion, it can be seen that some parents resist labelling because of the stigma and emotional consequences that labelling could have and this is especially true in countries where it is viewed as being an impediment (Dyslexia International, 2016). Redford (2017, p.1) states that as a result of her experiences as an teacher and as a mother to a dyslexic son who did not receive early intervention because of her denial as a mother, the challenge faced by parents when realising that their child has dyslexia, is moving from the “idealized version of their child to the real”.

1.4.5 Views of Teachers

School teachers are in a crucial position regarding the advice and information that they provide to parents. Thus far, I have been unsuccessful in my attempts to discover from literature, the views of South African teachers in mainstream and special schools about the label of dyslexia and labelling. Thompson (2014) conducted an investigation into the awareness of dyslexia in South African teachers teaching in mainstream high schools, but makes no mention of the label of dyslexia. The literature discussed therefore does not give the views of South African teachers. Redford (2017) states that her son did not benefit from early intervention not only because of her denial but also as a result of the advice given to her by her son’s teachers (kindergarten to fourth grade), who informed her that her son was too young for a formal diagnosis and that his challenges resulted from of a learning lag.

International literature shows that school teachers and postgraduate lecturers have differing views ranging from one end of the spectrum to the other. Taylor (2011) a university lecturer conducted research which indicated that the label of dyslexia can actually improve the self-esteem of learners who are struggling at school. She felt that the label of dyslexia was specific and therefore far more beneficial to the person than a non-specific label such as Special Education Needs (SEN). However, Elliot (2014) a university professor, educational psychologist and former special needs teacher provides an extreme view when he states that the label of dyslexia is meaningless, useless, should be abandoned, is used by middle-class parents who are afraid that their children will be judged as slow, lazy or stupid and is a waste of educational resources. There has been an outcry from many corners to this view.

1.4.6 Educational Institutions Views

Research indicates that an educational institution's motives for labelling plays an important role on the outcome. If the motive is for purposes other than for the intellectual and emotional growth of the labelled child and results in categorisation, it could lead to low expectations for this learner, who is often gifted in areas not focused on in traditional classrooms (Zembylas & Isenbarger, 2002). Whilst dyslexia is avoided or denied in some countries or institutions, Murphy (2017) states that educational institutions in New Zealand are recognising the label as being of value to both the parents and the child, in that the learning difficulty is identified and the label thus leads to the school recognising the tuition and assistance that the child needs, resulting in appropriate teaching.

Literature discussed thus far continually validates the need for this research to be conducted so as to fill a glaring gap in SA research. I end this review, which will continue in Chapter 2, with the views of Busby (2013), who states that proper labelling is important in order to receive appropriate services and accommodation both in school and in the workplace. Busby further cautions that failure to label could result in success both in academics and in life not being achieving. Based on this, my endeavour was to discover if my study will agree or contradict this view.

1.4.7 Theoretical Models influencing Dyslexia

Literature reflects the profound influence that theoretical models have on the way in which learning disabilities are viewed, including the impact that they have had on the way in which dyslexia is viewed, perceived and debated by many today. The main models influencing the lens used for viewing dyslexia are the medical and social models (Reraki, 2014). Such influences can be seen in the variation of the terms used for learning disabilities and reasons provided for this variation are often based on these models. Terms used include a learning disorder, a learning impairment, a learning difficulty or as barriers to learning. Bishop (2014) states that the word 'disorder' is not liked by some because it is viewed as having medical connotations that insinuates qualitative and not quantitative differences in learners. Terminology is thus important and alludes to the lens used to view dyslexia.

Landsberg (2011) a SA author, refers to the differences experienced in learning as 'barriers to learning" which she also uses as the title of her book. This term is echoed in Education White Paper 6 (EWP6) (DoE, 2001) which also refers to such learners as having barriers to learning.

This could be the effect of both Landsberg and the Department possibly being influenced by the social model of disability hereunder. Bornman and Rose (2017) state that the terms and descriptions used are important; for example, the term 'dyslexic person' places the focus first on dyslexia and then on the person, therefore it is far better to use the term 'the person with dyslexia' in that the person is placed first. Whilst this study will not singularly use the medical, social or positive models of disability, it is important to acknowledge the role that these theories have and are playing in decisions made around the labelling of individuals diagnosed with dyslexia.

The medical model views disability negatively as something innately wrong with the person, something lacking, that the person is therefore disabled as a result of having cognitive deficits (Treptow, 2017). The assessment of dyslexia being done by a specialist further reinforces this view (Armstrong & Squires, 2015). The medical model has a marked influence on the way in which medical professionals and teachers view the learning-disabled person, and methods of assistance according to this model includes medical or other such treatments. The disability is overemphasised, viewed as an impairment, and is placed as a central problem in the person's life that must be treated and rehabilitated (Mckenzie, 2013). The person is therefore viewed as the one to take responsibility for their challenges, to make the required adjustments to their behaviour and thereby fit into what is expected of them in society (Bell, 2010). The medical model sees the disability as a problem that belongs to the individual and does not see it as concerning anyone other than the affected person (University of Leicester, 2015).

The social model on the other hand appears to be less negative than the medical model and looks at how societies can assist the disabled person. This model therefore sees society as playing a role in assisting those with disabilities whether physical or intellectual. Haegele and Hodge (2016) believe that this model suggests that the construction of solutions for disabilities should not be directed to the individual, but rather towards society. Many are of the view that this model should be used as the frame for education practices. It is particularly obvious in EWP6 (DoE, 2001), which makes repeated reference to the removal of all barriers to learning so as to provide an educational environment that meets the needs of all learners. The SA Education Department's commitment to the removal of all barriers to learning within SA schools, is further reflected in the Policy on Screening, Identification, Assessment and Support (SIAS) which aims to ensure a transformed and inclusive education system, as advocated in the EWP6. The purpose of the SIAS policy is to focus on the removal of barriers, thus ensuring

improved access to quality education for all learners as well as to manage and support the teaching and learning processes required for learners experiencing barriers to learning (DBE, 2014).

Whilst the name 'positive psychology theory' appears to imply that other theories are negative, it was not derived as a result of negativity but grew as a result of recognising the imbalance in clinical psychology (Gabel & Haidt, 2005). These researchers refer to positive psychology as "the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups and institutions" (p.103). Positive psychology is based on three pillars identified as the study of positive emotion, the study of positive traits (strengths, virtues and abilities) and the study of positive institutions (democracy, strong families) (Seligman, 2002). It is therefore linked to both Bronfenbrenner's Ecological systems theory (Bronfenbrenner, 1979) as well as Maslow's Hierarchy of Needs (Maslow, 1943) in that it acknowledges the role and contribution played by those in the individual's ecosystems, and the influences of these ecosystems on the attainment of the individual's needs.

These three theories, amongst others, have had a profound influence on dyslexia and the lens used for viewing it. Theoretical models influence discourse with Haegele and Hodge (2016) stating that the language used to describe persons with disabilities influences interactions with and expectations of such persons, and language in turn, is influenced by the manner in which a disability is understood. Whilst this study acknowledges that other theoretical models exist that impact the lens used for dyslexia, the influence of the three models discussed above can be found in this research. Exploration of the *label* (medical model - diagnosis), the *environmental interaction* that the label has (possible social/medical model) as well as the *experienced influence* that the label has on the individual with dyslexia (possible medical/social/positive psychology) are found herein.

1.5 SITUATING THIS STUDY

We live in a world of labels. We are labelled from the time we took our first breath. People have however, chosen which labels are viewed as positive, which are viewed as negative, as well as appropriate or inappropriate and this is often done on behalf of others. All labels seen as deviating from the perceived norm, are viewed negatively and this is evident in attitudes displayed towards the labelling of dyslexia in schools, education, the workplace and in society in general.

Within education, the label of dyslexia is sometimes shied away from in favour of a more general label for the challenges experienced by those with dyslexia, as it is viewed as being unnecessary and as an additional burden to carry because of the stigma attached to it. Armstrong and Squires (2015) state that explorations into the social, emotional and psychological effects of dyslexia suggests that many with dyslexia have a negative and unproductive view of their educational experiences which has resulted in negative consequences for adulthood. Could this be the result of education's avoidance of the label and failure to recognise the needs of such learners? The EWP6[4], in providing guidelines on establishing an inclusive education and training system, states that learners experiencing barriers to learning must be identified early so that the appropriate support is given (DoE, 2001). Is that identification not a label where the learner is labelled as having challenges in learning and needing added support? The SA guidelines given for the implementation of Special Schools as Resource Centres state that to prevent learning barriers from occurring, which could result in learners not succeeding or being excluded from the education system, it is of utmost importance to ensure that the needs of such learners are effectively monitored and met (DoE, 2005). This research is of the view that the voice of the special needs' learner is critical to the discovery of the barriers, including insight into the label of dyslexia.

Decisions about dyslexia and the use of the label are made by those who do not have this learning challenge while research to discover the views of those with the label, is scant. Although the participants in this study were adults, the exploration of the label is situated in discovering the impact that the label has had on the life experiences of the participants. With focus starting with the educational influences experienced, reference is made to Article 12 of The United Nations Convention on the Rights of the Child (UNCRC) wherein it is stated herein that

> *the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child,....the child in particular be provided with the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body.....* (UN Committee on the Rights of the Child (CRC), 2009).

[4] Further discussed in Chapter 2.

It is only by talking to those directly involved that fixed assumptions can be challenged, and insight gained into personal and sensitive issues including the phenomenon only known to the person experiencing it and therefore invisible to others (Rubin & Rubin, 2012).

The importance of the source of these views are the persons with the disability, as attested to by the World Health Organisation (2011, p.225), wherein it is stated that "the voices of children with disabilities themselves must be heard, though they frequently are not". The advantages of doing so are evident in the study of Savaria et al. (2011) which reveals that children and young people should be active participants in matters that affect them as this will improve their self-concept and coping strategies. The main research question for this study is formulated, bearing in mind the question asked by Lauchlan and Boyle (2014) of whether the label will improve the individual's life and if the answer is yes, then it leaves no room for the argument against the use of labels; but if the answer indicates uncertainty, then the attaching of labels must be approached with extreme care.

1.6 RESEARCH QUESTIONS

This research provides insight into the feelings, attitudes and experiences of English-speaking SA adults who have been diagnosed with dyslexia. Focus is directed to diagnostic experiences, feelings towards the label of dyslexia, living with this label and the effects of dyslexia on the achievement of their needs. The primary research question is:

What are the described experiences of South African adults living with the label of dyslexia?

In seeking to achieve the purpose of this study, the main research question is supported by the following sub-questions based on the perspectives of the adult diagnosed with dyslexia:

1. What is dyslexia?
2. Which ecosystems are involved in the diagnosis and disclosure of the individual's dyslexia?
3. What were their family, education and peer experiences prior to being diagnosed and labelled with dyslexia?
4. What are their family, education, peer and society experiences subsequent to being diagnosed and labelled with dyslexia?
5. What is the impact of dyslexia on adulthood?
6. What is the view of adults diagnosed with dyslexia towards the label of dyslexia?

7. What effect has the label of dyslexia had on the individuals' attainment of needs identified in Maslow's hierarchy of needs?

1.7 PURPOSE OF THE RESEARCH

Despite the plethora of information that exists about dyslexia with multiple articles written by researchers such as Alexander-Passe (2006; 2008), Burden and Burdett (2005; 2007), Elliot (2014;), Humphrey (2002; 2003), Shaywitz (1996; 2003) and Snowling and Hulme (2011; 2012) to name just a few, writings that describe the subjective and inside world of the individual with dyslexia so as to disclose the feelings and views of those diagnosed with it, are scant and limited. This is especially true when researching SA academic literature sources on dyslexia. A glaring and obvious gap exists both internationally and locally. The need for research herein is acknowledged by Arishi, Boyle and Lauchlan (2017, p.14) wherein they state that "how children with disability labels feel about themselves is something worthy of investigation on a large scale". My literature search thus far into SA studies reveals the writings of Claassens (2007), Claassens and Lessing (2015), Flack (2009), Hoskins (2015), Thompson (2014) and Van Staden, Tolmie & Badenhorst (2009). These writings however, focus on the adolescents' self-perceptions and socio-emotional support needs, main stream school teacher awareness of dyslexia, learner school experiences and ways of enhancing the literacy skills of those with dyslexia.

In order to attempt to fill this glaring gap, the purpose of this study was to gain insight into the lived experiences of adults diagnosed with dyslexia and hence living with this label. Concurring with McNulty (2003), the choice of adults is based on the premise that they provide a wider reflection on their life experiences and therefore offer valuable information and insight, which is sparse and lacking in research. The primary aim of this exploration was to gain an understanding of what it is like to live with this label from their perspective. Descriptions provided by the labelled person, assisted in achieving the objective of this study, which ultimately decided if the label should be used or not. Decisions are made by relevant secondary parties such as schools, teachers, professionals and families amongst others, as to whether the label should be used or not. Are these decisions not the right of the dyslexic persons to make? This study focused on getting answers through the descriptions provided by adults who are living with the diagnoses and label of dyslexia.

1.7.1 Primary Aim

The primary aim of this study is to describe the reported experiences of South African adults who are diagnosed with dyslexia, and thereby describe the benefits or not of living with the label of dyslexia.

1.7.2 Specific Aims

In order to achieve the primary aim of this research, the specific aims are to collect first-hand information from adults who have been diagnosed with dyslexia to:

- Gain insight, through their descriptions, into their lived ecosystem experiences before and after diagnosis.
- Provide their views of the label of dyslexia and living with this label.
- Determine whether individual progression within Maslow's hierarchy of needs can take place for those living with the label of dyslexia.

1.8 THEORETICAL ORIENTATION OF THIS STUDY

In seeking a suitable theoretical and conceptual framework for this study, I was mindful that the frameworks should place the individual with dyslexia, in a central position. Bearing in mind the view of Gibbs and Elliott (2015) who stress that, despite the inherent component of literacy challenges, which includes dyslexia, the relationship that the individual has with their environment plays a role that must be acknowledged. Therefore, the frameworks selected must allow for inclusion of all experiences of others, with others including the various organisations and structures that interact and influence their experiences of the world in which they live. Examples of others are families, schools, educators, educational authorities and peers, who compositely contribute to the social meaning and experiences of dyslexia (Solvang, 2007). For these reasons, the theoretical frameworks chosen as fitting and suitable are Bronfenbrenner's Ecological Systems Theory, which was used in conjunction with Maslow's Hierarchy of Needs. Both frameworks were combined to form the conceptual framework of the study whereby Maslow's Hierarchy of Needs was placed in the centre of Bronfenbrenner's Ecological Systems Theory. The selected theoretical and conceptual frameworks enabled the researcher to place the individual in a central position at all times during this study.

Bronfenbrenner was a well known and influential psychologist in the field of developmental psychology. He was of the view that human behaviour could only be fully understood by

looking at the individual within the context in which they are found. Based on this premise, he developed his famous Ecological Systems Theory, which delineates five environmental subsystems that have an influence on an individual's development (Bronfenbrenner, 1994). He identified these systems, which he framed as circles surrounding the individual, as the Microsystem which is the nucleus, and followed in an outward order to the Mesosystem, Exosystem, Macrosystem and Chronosystem. A detailed discussion of these systems is provided in Chapter 3.

Situated within Bronfenbrenner's ecological systems theory (1979) is Maslow's Hierarchy of Needs, which was used to describe what life is like when living with the label of dyslexia, and to determine if the individual's needs are or are not being fulfilled by the label. Maslow's hierarchy of needs, referred to as a motivational theory, is depicted as a five stage/tiered pyramid model of human needs which starts at the bottom with physiological needs and progresses upwards to safety needs, belongingness and love needs, esteem needs and ending with the ultimate need of self-actualisation. The first four levels are often referred to as D-needs or deficiency needs and the final top level are B-needs comprised of growth or being needs (McLeod, 2018). Maslow believed that people are motivated to achieve certain needs and as the needs in each tier are met, the person moves to the next tier. Maslow based his theory on the belief that human actions are all directed to goal attainment (Maslow, 1943). Both the theoretical and conceptual frameworks are used to frame the questions asked by this study and hopefully reveal if individual progression within Maslow tiers can be achieved whilst living with the label of dyslexia. Results rendered might indicate the worth of the label. The theoretical and conceptual frameworks are further discussed in Chapter 3 of this study.

1.9 RESEARCH METHODOLOGY AND DESIGN

As this study intends to describe the experiences of individuals living with the label of dyslexia, the study is placed within the interpretive paradigm. The paradigm was found most appropriate for this study as the aim of interpretivism was not to predict what people will do but to describe how individuals create meaning of their worlds (Christiansen, Bertram & Land, 2010). Therefore, a qualitative approach and phenomenological research design was used for the research conducted in this study. The researcher was the primary instrument of data collection and the analysis of the data collected, aimed at answering the research question asked by this study. Qualitative research enables the researcher to explore and understand the lived experience and meaning that individuals ascribe to a social or human problem (Creswell, 2014).

Thereby providing a holistic enquiry and allowing the researcher to gather data that will provide insight into the subject matter. Qualitative research provides depth to the subject matter being explored as it enables the collection of both textual and verbal data (Christiansen et al., 2010).

The researcher is mindful that it is imperative that the research design selected should be one that prevents and restricts personal bias. Groenewald (2004) states that the aim of research is to accurately describe the phenomenon as well as to remain true to the evidence and understand it from the perspectives of the people involved. Therefore, Husserl's transcendental phenomenological research design was selected as most suited to this qualitative study as it enabled and provided an accurate description of the research conducted, and allowed for the findings to be presented free from bias, or where such bias has been noted, possibly restricted. It enabled the researcher to describe the lived experiences of the phenomenon experienced by the participants (Creswell, 2014). Phenomenology "can make the qualitative analysis of phenomena both rigorous and scientific" (Giorgi, 2005, p.75) and this results in the provision of findings that are trustworthy.

1.9.1 Sampling

McMillan and Schumacher (2014) state that the participant size of qualitative research is small compared to that of quantitative research and is influenced by the purpose and focus of the study, the data collection strategy, the availability of research participants and the redundancy of data (would more participants offer more insight?). Bearing in mind that the researcher did not have direct access to the names of participants and was reliant on a third party, a minimum of six and a maximum of ten adult participants both male and female, between the ages of 18 and 40 were viewed as optimal for this research. This was compliant with phenomenological studies, which usually has between three and ten participants (Creswell, 2014). Marshall and Rossman (2016) state that an advantage of a small sample size is that it enables the researcher to create depth and develop relationships with the participants. The sample in this study comprised of eight adults (five females and three males).

A multistage or clustering procedure, referred to in Creswell (2014), was followed whereby the researcher requested the assistance of a third party to provide the names of individuals who satisfied the criteria of the study and who might volunteer to be possible participants. Individuals who agreed to be participants were selected. A criterion-based sampling strategy

was therefore used. This sampling strategy is suited when the individuals studied, are representative of others who experience the same phenomenon (Bloomberg & Volpe, 2016).

The primary reason for focusing on adults and not younger children, is based on my view that they would have more to disclose because of being older and therefore richer in their experiences. I interviewed research participants from various social levels and included participants who were educated in different schools (government and independent/private) found in SA. This allowed a more rounded perspective and enhanced the value of the findings.

1.9.2 Instrumentation and data collection techniques

As qualitative data are textual, verbal or graphic and provide in depth information (Christiansen, et al., 2010), the instrument of research is the interview. Individual semi-structured interviews were used as a means of data collection and were between 1-2 hours in duration. Following an interview guide, participants were interviewed by the researcher with the use of both open-ended and close-ended questions. Interviews only concluded when saturation on the topic was reached; however, follow up interviews were conducted, if it was deemed necessary. As the data collected were verbatim accounts to the questions asked, digital audio recordings were used as a means of ensuring that the data collected was available for reliability checks (McMillan & Schumacher, 2014).

Boudah (2011) advocates triangulation as a technique that increases the truth value of research and this is achieved by using more than one source of information in a study to confirm a concept or idea. Triangulation forms an essential component of phenomenology as stipulated in Giorgi (2008) as a means of ensuring validity. Therefore, apart from the interviews, the researcher kept a research diary which included observations, and reflections of the researcher, incorporating reflections with reference to literature.

1.9.3 Data analysis and interpretation

Data analysis and interpretation was guided by the theoretical and conceptual frameworks selected for this research. As a result of the researcher's bias, as stated in the rationale of this research, it was imperative that phenomenology was used to analyse the data, thus ensuring that the results of this study were true and authentic, and that the data collected was described as accurately as possible. All aspects and areas of influences were noted, thereby providing a more holistic base for analysing the data. Therefore objectivity, which is referred to by

McMillan and Schumacher (2014) as unbiased, open-minded and not subjective, and as a necessary characteristic in educational research, was achieved. Data obtained from the transcripts of the audiotapes were analysed within the parameters of the selected theoretical frameworks. The analysed data was sorted into themes with categories and sub categories within both frameworks.

1.9.4 Credibility and Trustworthiness

Credibility and trustworthiness are essential components of a sound qualitative study and used as the ultimate yardstick of measurement, as it addresses the accuracy of the research and hence the data that is produced. Every qualitative inquiry into human experiences must address these issues to ensure that the study is one that is viewed as reliable. Lincoln and Guba (1985) addressed this where they stated that research is credible when it reflects the actual lived experiences of the research participants, and that credibility in research leads to trustworthiness, a concept whereby the validity of the work is measured. Boudah (2011) states that the trustworthiness of qualitative research refers to how the researcher assures that the findings described in the study are credible and that these findings and conclusions are appropriate and fully developed. The concept of trustworthiness, outlined by Lincoln and Guba (1985), is measured by credibility, transferability, dependability and confirmability and is restated in Lincoln, Lynham and Guba (2018) as constructs to observe in qualitative research. The phenomenological research design selected for this study contributed towards the credibility and trustworthiness of this study.

1.9.5 Research Ethics

In all research, and especially in research of this nature, ethics forms an important component. Following the rules prescribed by Unisa, application was made to the Unisa College of Education Ethics Review Committee wherein an ethical clearance certificate for the study was sought. Included in this application was an outline of the ethics that would be observed by the study. Obtaining the contact details of possible participants was made after this certificate was received. Following the process indicated on my ethical clearance application form, written consent was sought from each participant prior to data collection.

Respect must be shown to the research participants who have agreed to be participants; therefore, the researcher was mindful of this virtue throughout the research process. Researchers are often faced with the dilemma of making sure that they have a balance between

their pursuit of the data for the study and the rights of the research participants. This was especially pertinent to this study where the research participants might have faced negativity as a result of their challenges, the stigma that they might have experienced stemming from this or even their own internal conflict. Respect, autonomy, justice, beneficence, non-malfeasance, integrity, fidelity and responsibility are regarded by Christiansen et al. (2010) as the eight general ethical principles that should be observed by the researcher and these served as guidelines in this research.

1.10 DEFINITION OF KEY CONCEPTS

Definitions, descriptions and explanations of the key concepts used in this research are given in this section, so as to provide the reader with an understanding of what is being researched, thus eliminating any uncertainty or vagueness.

1.10.1 Literacy

The term literacy is equated by many as referring to reading and writing. The definition selected by this study takes more than just these two components into account. The academic definition of literacy suited to this study was taken from the United Nations Educational, Scientific and Cultural Organisation (UNESCO) who state that "Literacy is the ability to identify, understand, interpret, create, communicate and compute using printed and written materials associated with varying contexts. It involves a continuum of learning in enabling individuals to achieve their goals, develop their knowledge and potential, and participate fully in their community and wider society" (UNESCO, 2004).

1.10.2 Labelling

This study found the description of labelling provided by Gold and Richards (2012) as fitting for the purpose, wherein they describe labelling as assigning a descriptor to an individual based on their selected behaviour and/or physical characteristics. This label places the individual into a specified group bearing the same characteristics and it thus makes the individual distinguishable. Labels can be discriminatory, an aspect determined by society. Therefore, labels can be seen as either good or bad.

1.10.3 Learning Disabilities

Much debate exists around the definition of learning disabilities. As a result of a lack of consensus, various definitions can be found. This research favoured the use of the definition

provided by the National Joint Committee on Learning Disabilities (2016, p.1) which states that: "Learning disabilities is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the life span. Problems in self-regulatory behaviours, social perception, and social interaction may exist with learning disabilities but do not by themselves constitute a learning disability. Although learning disabilities may occur concomitantly with other disabilities (for example, sensory impairment, intellectual disabilities, emotional disturbance), or with extrinsic influences (such as cultural or linguistic differences, insufficient or inappropriate instruction), they are not the result of those conditions or influences."

1.10.4 Special education in South Africa

Special education in South Africa is provided in special schools, as well as in remedial or special classes in mainstream schools (DoE, 2001). Providing for the needs of learners who experience barriers to learning in both mainstream and special needs education, is in keeping with the Education White Paper 6 that focuses on building an inclusive education system. This system acknowledges that all children can learn and that all learners have different learning needs that make them different.

1.10.5 Special needs schools

Special needs schools are also referred to as LSEN schools (Learners with Special Education Needs). These schools accommodate the learning needs of learners who experience mild to severe barriers to education and who require additional education support (DoE, 2001). Special needs schools are staffed with educators and various professionals with specialised skills to assist and improve the education of learners experiencing barriers in mainstream education.

1.11 CHAPTER OUTLINE

This thesis, focused on the first-hand experiences of adults who are diagnosed with dyslexia and hence living with the label of dyslexia, is comprised of six chapters outlined hereunder:

Chapter 1

This chapter provided insight into the introduction and background to the research and included the present situation with regards to dyslexia, the label of dyslexia and seeking to understand

the factors that impact on living with this label. A discussion of literature, the research methodology and design selected to ensure credibility and trustworthiness, the research ethics observed, as well as the clarification of key concepts used in the research, were identified and discussed.

Chapter 2

A review of the literature is conducted commencing with the history of education in SA followed by a discussion on the EWP6. Thereafter, dyslexia as a learning disability is discussed commencing with the history of dyslexia and culminating with the term and label of dyslexia in the 21st century. Thereafter the concept of labelling is discussed including the advantages and disadvantages of labelling. The views and writings of professionals, academic researchers, blogs and various internet sites are referred to.

Chapter 3

The theoretical and conceptual frameworks underpinning this research are discussed, together with reference to their role in this research and the reasons for their selection. A literature review is conducted wherein focus is placed on the individual who is diagnosed with dyslexia.

Chapter 4

This chapter focuses on the empirical exploration to be conducted herein. A discussion on the research design and methodology selected for this research is found herein. Detailed information on the research style, theoretical frameworks, sampling, data collection, analysis of data as well as issues of ethics, credibility and trustworthiness are provided.

Chapter 5

This chapter examines the interviews undertaken. These are presented and the empirical findings are discussed together with the findings of the literature study to provide insight into the exploration.

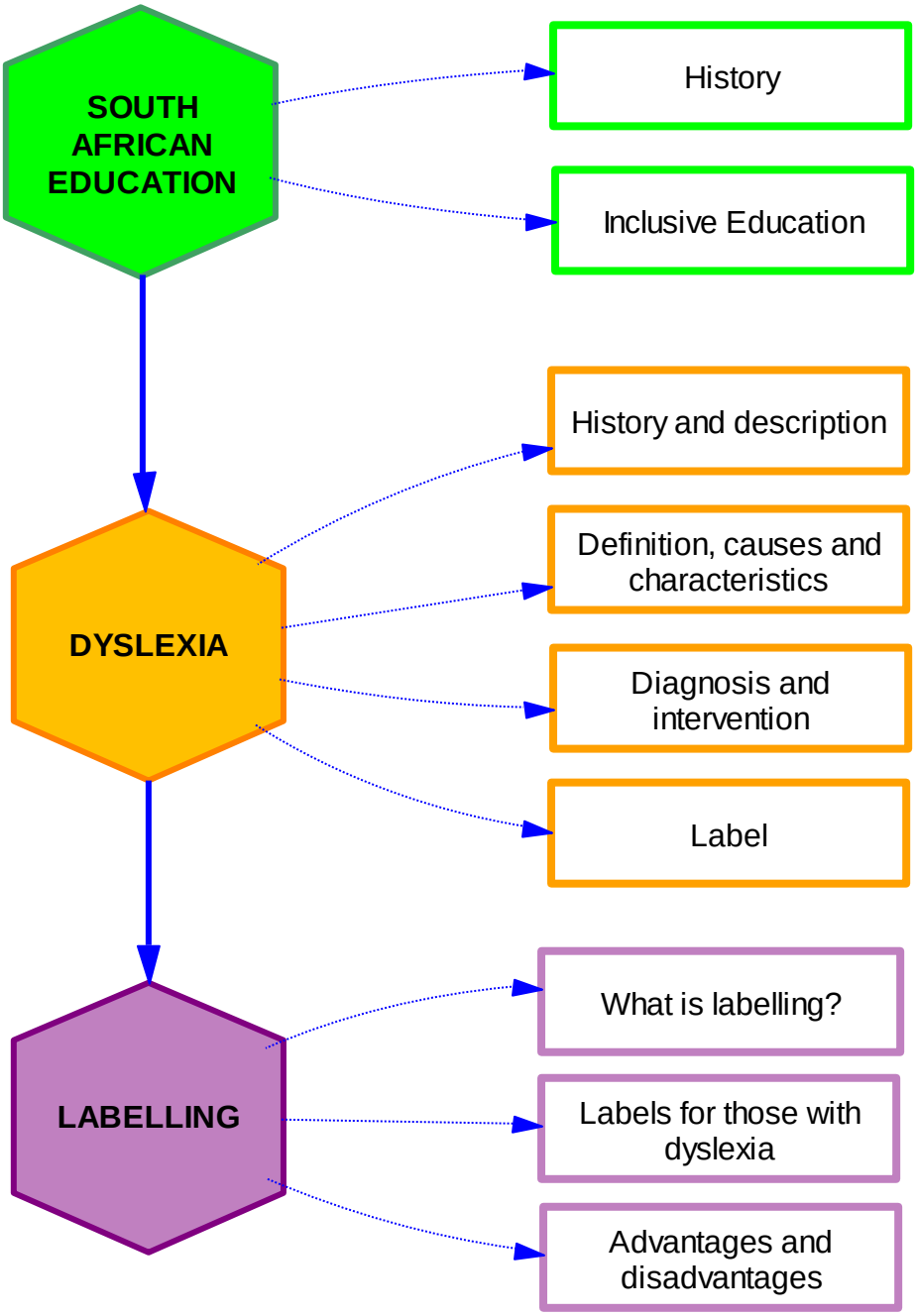
Chapter 6

In the final chapter, all the significant findings of the research are summarised. Conclusions are drawn, limitations discussed and recommendations for further research are made.

CHAPTER 2

LITERATURE REVIEW

OVERVIEW OF THE CHAPTER



2.1 INTRODUCTION

Research into the lived experiences of those living with the label of dyslexia is minimal, with a glaring gap existing herein. This has resulted in Arishi et al. (2017) emphasising the value of conducting such research, as using the voice of those living with a disability label to express their feelings and experiences, provides valuable insight into their lives. This literature review has enabled the researcher to gather and reflect on what is known about dyslexia and labelling, living with this label, and referring to controversies, contradictions and changes in thought that have happened over time, resulting in the accumulation of the knowledge that is now known (Yin, 2011). I was mindful that further reading into dyslexia and labelling could enable me to examine my bias and personal views that agree and differ with the published research and writings, a process stated by Rubin and Rubin (2012) as being a positive component of credible research.

Even though the participants in this study were adults, education has underpinned their discovery of dyslexia or the realisation of experiencing literacy challenges; therefore, educational experiences are included in this review. This chapter begins with a brief synopsis of SA education, followed by a discussion on dyslexia, labelling, as well as the known experiences of those who have been diagnosed and living with the label. These experiences discussed are guided by Bronfenbrenner's Ecological Systems Theory (Chapter 3). Using the psychological needs tiers from Maslow's Hierarchy of Needs (Chapter 3), the possible psychological effects of dyslexia are discussed.

2.2 SOUTH AFRICAN EDUCATION

As this study is located in SA, the literature review provides background to the South African education system in which the participants of this study were educated. This is followed by a brief discussion of Inclusive Education, a system that is currently informing the education practices of modern-day education in South Africa. Figure 2.1 provides a synopsis of the South African education system pre- and post-1994, thus providing an illustrative backdrop against which the discussion hereunder can be understood.

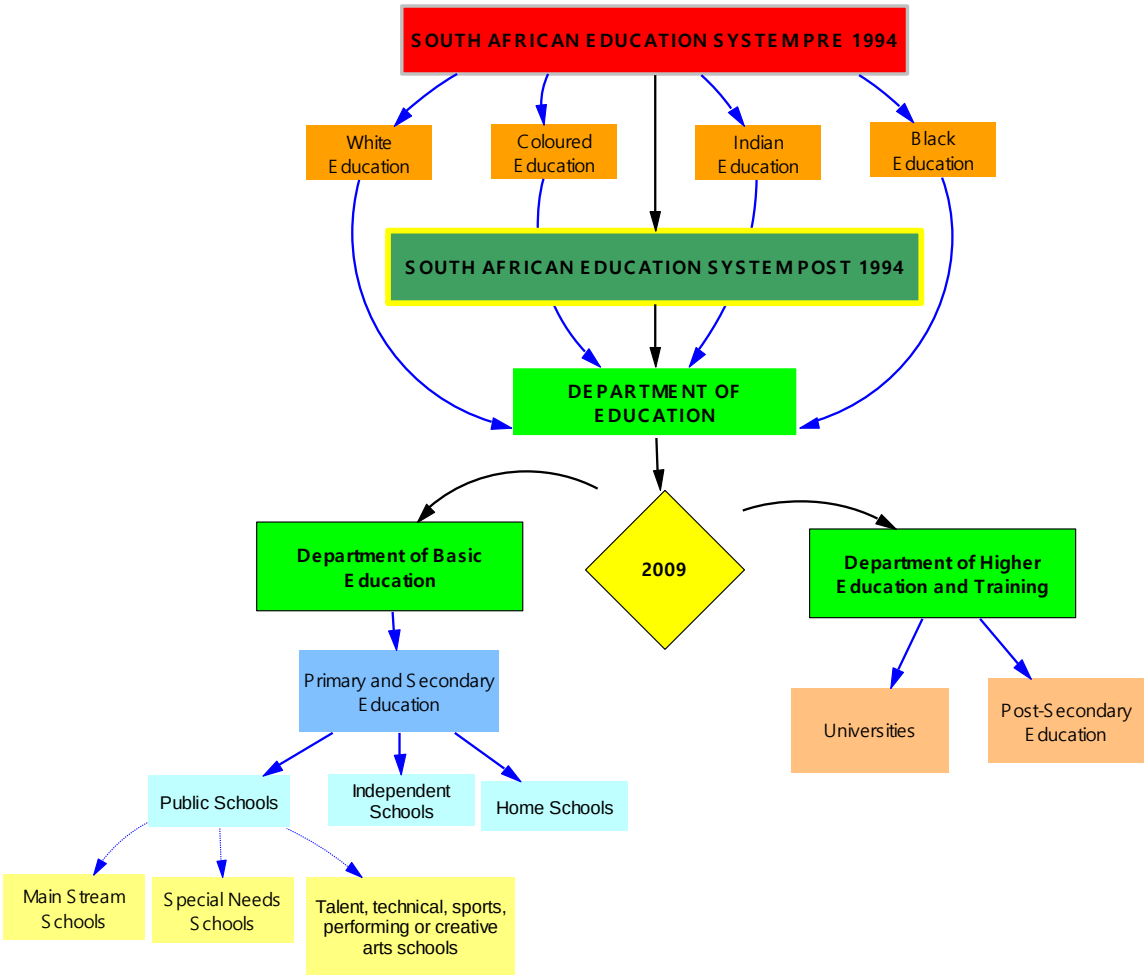


Figure 2.1: Overview of the South African Education System

2.2.1 Education Pre-1994

In order to understand the context in which this study is placed as well as the rational given for the undertaking of this study, it is important to briefly provide a brief historical synopsis of education in SA. Apartheid was introduced in SA in 1948 and called for the separate development of the four racial groups in SA (South African History Online, 2016). The word apartheid when translated from Afrikaans into English means "apartness". During apartheid, the education system was divided along racial grounds with each of the four race groups (White, Coloured, Indian and Blacks) having its own controlling education departments, resulting in a total of fifteen different education departments (Christie, 1991). Varying government monetary allocations were given to the education departments of each race group with the disparity being enormous. De Waal (2013) indicates that in 1982, the apartheid government spent on average R146 for that year on the education of a Black child, whilst R1211 was spent on a White child. Therefore, the White group received the most, whilst Bantu

education (the name given for the education of Blacks) received the least and the other two race-group's monetary allocation fell in between. This disparity had a marked effect on the quality of education as well as on the facilities available for each race group.

Flack (2009) states that as a result of the White group being more privileged and receiving more money, they had access to schools providing mainstream education, remedial education and special needs schools. Such schools were however, scarce and limited for the other race groups. This imbalance, referred to in the EWP6, states that schools for "white disabled learners were extremely well-resourced, whilst the few schools for black disabled learners were systematically under resourced" resulting in many learners with a disability facing challenges in gaining access to education (DoE, 2001, p.9). Learners with learning disabilities, including dyslexia, in the Coloured, Indian and Black race groups were easily lost in the education system and their challenges were not understood by the teachers as a result of their inferior teacher training. However, with the advent of democracy in 1994, major changes occurred in the SA education system with attempts at past imbalances being addressed.

2.2.2 Education Post-1994

Guidelines for change to education was provided in the South African Schools Act (SASA), 1996 (Republic of South Africa, 1996) implemented from 1 January 1997 with the aim of providing a uniform system for organising, governing and funding schools that provided education for learners from Grade R (Reception) to Grade 12. The Act was intended to control education as well as rectify the imbalances that occurred under the apartheid system. Currently two national departments govern education in South Africa. These are the Department of Basic Education (responsible for primary and secondary education) and the Department of Higher Education and Training (responsible for tertiary and vocational training). The nine provinces in South Africa also have their own education departments. Prior to 2009, there was only one national Department of Education. Historically, special needs education or specialised education and support services only provided for a small percentage of learners in South Africa (mostly white) and existed in a separate education system to mainstream education. Today public mainstream schools attempt to integrate learners with disabilities into the school through Inclusive Education. Special needs schools still exist. For the purpose of this study, I attempt to describe the current classification of schools in SA depicted in Figure 2.1, but will also refer to alternative names or descriptions since some of the participants in this study attended schools prior to 2009.

a) **Public schools** comprise of:

- Mainstream or ordinary schools are where inclusive education has been in place since 2004, and where most learners in South Africa attend. Learners have a broad selection of subjects and can attend these schools until Grade 12.
- Special needs schools are also referred to as LSEN schools (Learners with Special Education Needs). These schools are organised according to the programme of specialisation. Often learners attending a special needs school might have a combination of challenges. Special needs schools might offer learners additional support such as psychological, medical, physiotherapy, occupational therapy and speech and language therapy.

  Some examples of special needs schools are:

  i. Special or vocational schools. These schools usually are for learners with mild intellectual challenges who cannot cope with the academic demands in mainstream education. Depending on the particular school, vocational subjects, for example, woodwork, metalwork, building, plumbing, hairdressing, cookery, needlework, graphics and design, computer literacy and various other practical subjects are taught. The aim of these schools is to prepare learners for the employment market. Formal schooling ends at the Grade 10 level.
  ii. Schools for learners who are severely intellectually disabled. The focus at these schools is mainly behaviour adaptation and communication.
  iii. Schools for learners experiencing learning barriers (also called remedial schools). Usually these learners cannot cope academically at mainstream schools or experience very specific barriers. Learners attending these schools will have an average and higher intellectual ability and might be at the school for a short term or long-term placement. Although not all of these schools offer all education phases, learners can achieve Grade 12 by attending these schools.
  iv. Schools addressing physical disabilities. Different special needs schools exist for learners who experience similar physical impairments; for example, a school for the deaf, the blind, for learners with cerebral palsy, epilepsy and autism.
- Talent, sport, performing or creative arts schools provide education that focuses on delivery of a specialised curriculum in these areas. But the curriculum is

adapted and differentiated to meet the individual needs of the learners. Hence, a full range of academic subjects in addition to the chosen speciality subjects is offered up to Grade 12.

Public schools are controlled by a governing body comprised of the school principal as the head, and elected members including teachers, parents, staff members who are not teachers and learners from the school who are in Grades 8 to 12 (DBE, 2019). Funding is provided by the state on an 'equitable basis' to ensure the rights of learners and to rectify the inequalities of the apartheid era (DoE, 2006). All learners pay school fees (the same amount for all learners within a grade irrespective of their curriculum or extra curriculum activities), the amount being that which has been agreed to by the majority of the parents attending a special school meeting (DBE, 2019). Schools therefore vary in the school fees charged; however, some schools, as determined by the Minister of Education, are exempted from charging fees (Republic of South Africa, 1996).

b) **Independent schools,** previously referred to as private schools prior to the SASA of 1996, are privately established, funded and maintained schools. Whilst they are responsible for their costs, some independent schools are granted a subsidy by the Minister of Education. All independent schools have to be registered by the head of their provincial education department. The standards of independent schools cannot be inferior to the standards of public schools and they cannot discriminate on the basis of race. Grade 12 examinations at independent schools either fall under the body responsible for these examinations in public schools, namely the Council for Quality Assurance in General and Further Education and Training (Umalusi), or they fall under the Independent Examinations Board (IEB), which is an independent body that offers certified assessments. The IEB, which is accredited by Umalusi, was founded in 1989 during the apartheid era with the aim of ensuring a non-racial assessment body for Grade 12 (IEB, 2019).

c) **Home schooling** allows parents to apply to the Head of the Education Department within their province for the learner to be registered and be educated from within their home. The minimum requirements of the curriculum followed at public schools have to be met, and the standard of home schooling cannot be inferior to that of public schools.

In this 21st century, formal primary and secondary education for SA learners is divided into four phases namely the:

- Foundation phase - Grades R to 3;
- Intermediate phase - Grades 4 to 6;
- Senior phase - Grades 7 to 9; and
- Further education and training phase - Grades 10 to 12 (DHET, 2017).

School attendance from the age of seven until the end of the year in which the learner turns 15, is compulsory and focus in each phase is placed on literacy, numeracy/ mathematics and language (DoE, 2006). Learners who successfully complete Grade 9 receive a General Education and Training Certificate (GET) (Western Cape Government, 2013), whilst those who complete Grade 12 receive a National Senior Certificate (NSC) which is commonly referred to as a matric certificate. This certificate is the main school-leaving certificate in SA.

2.2.3 Inclusive Education

After the apartheid era, changes were made to transform SA's existing education system. The rights of all to a basic education and to further education was based on the SA Constitution of 1996, Section 29 (South African Constitutional Assembly, 1996). A team made up of the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee for Education Support Services (NCESS), were tasked to explore all aspects of special needs as well as the support services needed to ensure a system that would cater for the needs of all learners (NCSNET, NCESS, 1997). This exploration by the above committees was "based on the belief that the central challenge facing education is that of recognising and addressing the different or diverse needs of the entire learner population and minimising, removing and preventing barriers to learning and development, thereby promoting effective learning among all learners" (p.2).

In 2001, Inclusive Education, a system followed by many countries world-wide, strongly advocating the inclusion of learners with disabilities in mainstream education, was introduced. It is based on the Salamanca Statements guiding principle "that schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions" (UNESCO, 1994, p.6). In aligning with this statement adopted by 92 countries and 25 international organisations, SA attempted to eradicate the injustices of the past especially in

special education where most learners with disabilities did not benefit from specialised education. Inclusive education was introduced on the basis of Act 108 of 1996 of the SA Constitution, which places emphasis on the "values of human dignity, the achievement of equality and the advancement of human rights and freedoms" (DoE, 2001, p. 11). The SA Department of Education published the White Paper on Inclusive Education that outlined the plans for this inclusive education system, that would be a learner-centred approach to teaching and learning and would address the needs of all learners, including those with special educational needs into one inclusive education system (DoE, 2001).

The EWP6 advocated the differentiation of curriculum delivery in mainstream education/full-service schools, so as to accommodate and provide for all learner needs and to ensure that support systems were available for both learners and schools. Therefore, all learners, irrespective of their special education needs or disabilities, would be included as learner needs are viewed as arising out of the system and not from the learner. Inclusive education therefore concedes that learning within one system is possible for all with the removal of all barriers faced by learners, such as overcrowded classes, language of instruction, teaching methods, appropriate learning materials, exclusionary policies, time constraints and assessment (DoE, 2001). Crucial to the success of inclusive education are the teachers which the EWP6 states will require development and improvement of their skills and knowledge, as teaching will have to satisfy individual learner needs. Inclusive education views disability not only in medical terms but the rights of the disabled is acknowledged and changes are made to the system to exclude impediments for such learners (DoE, 2005).

The EWP6 states that within an inclusive education system, special schools would be integrated into one education system, that such schools are critical to the transformation to inclusive education, and would therefore be "strengthened and not abolished" because of their value in providing essential education services for learners with moderate to severe disabilities (DoE, 2001, p.3). This paper states that special schools will act as resource centres (SSRC) to full-service schools in providing and assisting mainstream teachers with the expertise and support that they need to teach learners that face mild to moderate learning disabilities, through learning support programmes. Learners with moderate disabilities can attend a SSRC for in-depth support (short term special school) and then possibly transfer to a mainstream school after successful support (DoE, 2005). The importance of full service schools being closely

associated with an SSRC, is that as one-year or one-term teacher exchange schemes could be implemented and as such be cost effective is stated (DoE, 2005).

Validating their commitment to the removal of all learning barriers, as well as to ensure the successful implementation of the EWP6, the Department of Basic Education (2014) created the Screening, Identification, Assessment and Support policy (SIAS) (DBE, 2014). SIAS is directed at ascertaining the support needs of all learners and thereafter enabling them, irrespective of their learning needs, to be educated and receive the needed support from their local schools. Guidelines are provided, where the aim is to achieve a transformed education system that is not only inclusive, but also one that ensures that the interests of the learner are always taken into account. Procedures that must be followed to screen, identify, assess and support learners, who require additional support, are indicated. To achieve inclusion, the education system consists of:

- School-based Support teams, which are established by schools to put in place and co-ordinate the school, learner and teacher support to ensure an inclusive education environment that provides "learning, care and support" to all;
- Special Schools, which are equipped to provide specialised full-time or part-time education to learners requiring "high-intensive" education and support; and
- Special School Resource centres which are special schools that provide education to those who extra educational support as well as provide support to ordinary and full-service schools (DBE, 2014, p.9).

This policy further indicates that additional support including curriculum differentiation, as well as the provision of assistive devices and assistive technology such as specialised computer software, will be provided to learners needing it. Such support is relevant to those with dyslexia as it will assist with their literacy challenges. Currently, many public-school learners in South Africa with dyslexia can be found in mainstream schools, short-term special schools, long-term special schools, as well as technical schools. The discussion thus far on the SA education system, as well as insight into the inclusive education policy, provides insight into the location of this study and forms an important component in the understanding of the environment in which the learner with dyslexia is placed. The next section reviews literature to gain a better understanding of dyslexia, its history, assessment, diagnosis and interventions, as well as labelling and how this has affected the learning process.

2.3 DYSLEXIA

This section will provide a review of the origins of dyslexia, the various aspects of this learning challenge and present, as well as discuss the controversies and debates surrounding dyslexia as well as their impact.

2.3.1 History of dyslexia

The roots of dyslexia are traced back to the medical field where this challenge was first identified and named. It was first referred to as 'word blindness' in 1877 by Adolph Kussmaul, a German neurologist, who became aware that some of his patients, despite being of normal intelligence and receiving a fairly good education, could not read properly (Lawrence, 2009; Selikowitz, 2012). Unlike Sir William Broadbent, who five years earlier stated that such cases were accompanied by speech disturbances or amnesia, Kussmaul recognised this challenge as an isolated symptom in the individual and is quoted as saying "a complete text-blindness may exist, although the power of sight, the intellect, and the powers of speech are intact" (Hinshelwood, 1917, p.1). Ten years later in 1887, Rudolf Berlin, a German ophthalmologist, stated that the term 'word blindness' should be replaced with the word 'dyslexia' as this word was in line with usage in international medical literature. Berlin had used it to describe stroke patients who had lost the ability to read, despite having good vision, hearing and other cognitive skills. The change in term however, took many years.

Up to 1896, articles on this challenge had only been written in medical journals, reinforcing that it belonged in the medical arena and thus began its association with the medical model of learning that was dominant during this time. However, this association changed in 1896 when word blindness as a challenge, was first reported in an educational context by W.P. Morgan in his paper *A Case of Congenital Word Blindness*, resulting in the challenge being viewed as belonging in the educational sphere. Morgan described a boy who was bright, of average intelligence and had good eyesight but experienced great difficulties in reading, writing and spelling. In line with Kussmaul's term of 'word blindness' Morgan (1896, p.1378) stated that the printed word conveys "no impression to his mind. . . . his memory for printed words is defective or absent. . . seems to have no power of preserving and storing up the visual impression produced by words. . . visual memory for words is defective or absent." Reference was made by both Morgan and Kussmaul that words could not be read but music symbols and some letters could be read, that such persons have no mental or physical defect and that they can be taught to read if the correct teaching methods are found (Ford, 1928).

'Word blindness' was also used by Dr James Hinshelwood in his 1917 book *Congenital Word Blindness.* This term was used throughout the early twentieth century and it was only in the mid-1930s that the term dyslexia became commonly used (Lawrence, 2009). Irrespective of the term used to describe this challenge, it was indicated that the most hopeful element of congenital word-blindness was that all reported cases had successfully been taught to read (Ford, 1928). In 1937, Samuel Orton perceived dyslexia as a consequence of neurological and environmental processes resulting in it being defined within a psycho-educational discourse and not in a biomedical one, thereby transforming the way in which it was understood, thus leading to the development of specific methods of instruction to minimise the symptoms (Macdonald, 2013).

Since its identification in 1877, dyslexia is viewed as the most studied and well-known learning challenge. Dyslexia research is found in all sub-divisions of psychology as well as in education (Armstrong & Squires, 2015). Figure 2.2 depicts the range of disciplines and sub-disciplines in which researchers have explored dyslexia over the last 30 years.

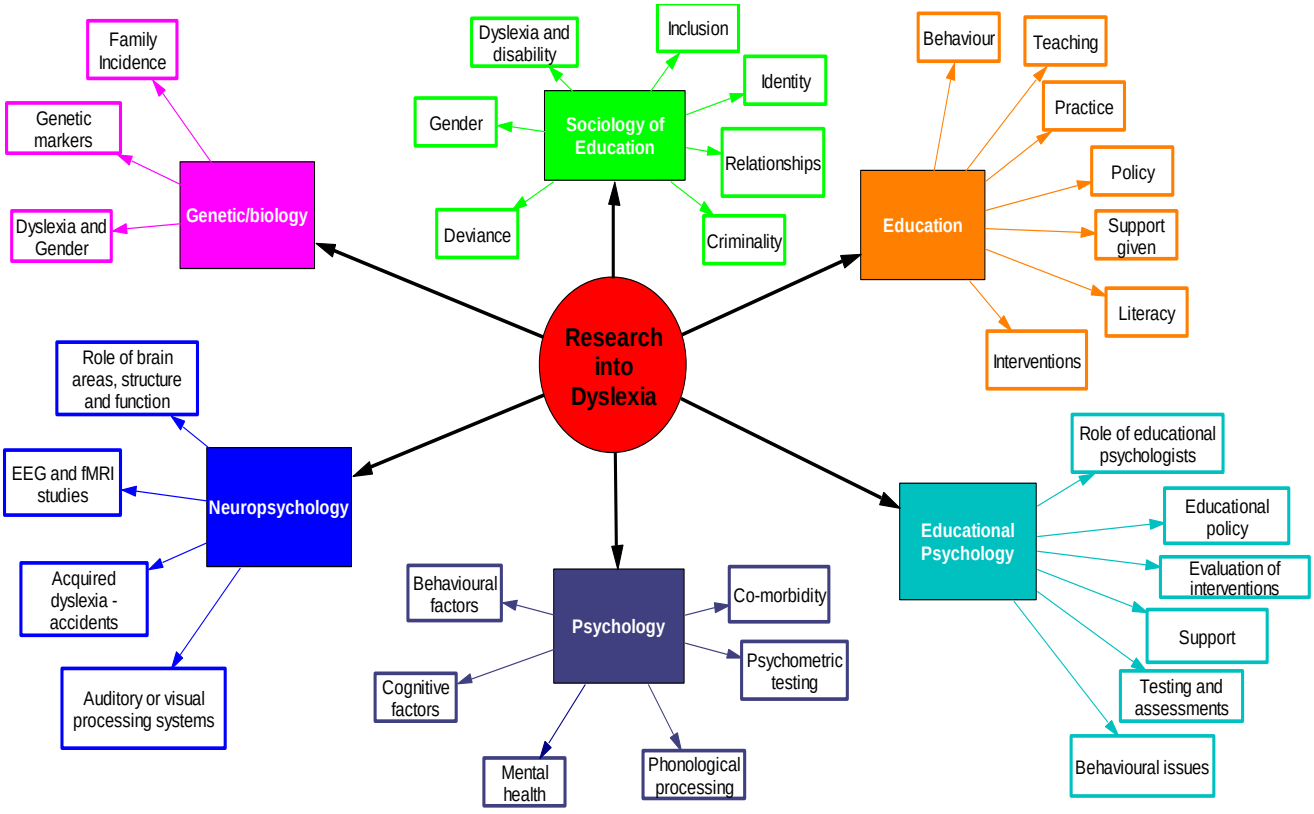


Figure 2.2: Disciplines and sub-disciplines explored in dyslexia research (adapted from Armstrong & Squires, 2015, p.4-5)

However, despite the various disciplines and sub-disciplines that have explored dyslexia, there is little agreement on most aspects of this learning challenge, including the definition and diagnostic criteria that should be used in assessment (Petretto & Masala, 2017).

2.3.2 What is dyslexia

The word dyslexia is of Greek origin and literally means difficulty with words or 'absence of language' as seen in the prefix *dys* meaning 'not', 'difficult' or 'absence' and the suffix *lexia* meaning 'words', 'reading' or 'language' (Bornman & Rose, 2017; Burden & Burdett, 2007). Dyslexia is therefore a literacy challenge, regarded as *the* most common and extensively studied learning challenge which affects 80% of individuals who have a learning challenge (Shaywitz, Weiss, Saklofske & Shaywitz, 2016). These researchers state that it is historically one of the oldest identified learning challenges and a key feature is that it is an unexpected difficulty in relation to the intelligence of the person. At least one in 10 people is dyslexic, equating to about 700 million children and adults worldwide who are at risk for remaining illiterate and thereby experiencing social exclusion (Dyslexia International, 2014). In SA, one in ten people is dyslexic equating to approximately 5 million South Africans who have literacy challenges at school or in the workplace (Pienaar, 2013). Therefore, it is of vital importance that dyslexia is recognised, as it impacts on education at all levels (Gallardo, Heiser & McLauglin, 2015), and hence society. However, it appears to be the least understood learning disability, by both parents and teachers, and is either being undetected or ignored in the educational system (Holloway, 2012). Despite dyslexia's prevalence and being extensively studied, it remains controversial, with various descriptions and views given, and whilst there is a difference in the wording, similarities abound.

Dyslexia is described by Shaywitz, Gruen, Mody and Shaywitz (2017) as a specific (not general) learning challenge, neurobiological in origin and characterised by challenges with accurate and/or fluent word recognition, together with spelling and decoding challenges. Rose (2009) describes it as a learning difficulty affecting the skills involved in accurate and fluent reading and spelling, as a result of challenges with phonological awareness, verbal memory and verbal processing speed. Siegel (2016) states that it as a language disorder arising from difficulties with hearing and confusing sounds within words, isolating and manipulating these sounds and the inability to retrieve the pronunciation of letters and groups of letters. Hudson, High and Al Otaiba (2007, p.512) describe dyslexia as "a disorder of the language processing systems in the brain" and challenges experienced are not caused by laziness or not trying, but

as a result of differences in the brain that makes them learn differently to their peers. Anderson and Meier-Hedde (2011, p.289) state that dyslexia is a "marked dysfluency in reading" that occurs as the child gets older. As a result of this lack in fluency, dyslexic readers will guess, fumble or attempt to phonetically sound words that their peers are able to read fluently (Hudson et al., 2007). The above variations in the description of dyslexia whilst similar are possibly the result of the various forms and types of dyslexia that exists.

Individuals can either have developmental dyslexia, which is congenital and often hereditary, or acquired dyslexia, which results from a brain injury or a disease (Henry, 2015). Within both developmental and acquired dyslexia, various types and forms of dyslexia are identified. Inshakova and Arkhipova (2011) state that the latest research indicates that three types of dyslexia are found; namely, *semantic* dyslexia, where the person can read fast but with little understanding, *technical* dyslexia, which is related to speed and those with it cannot learn to read fast but they understand text and lastly, *combined* dyslexia which is the most severe as the person is unable to read fast and unable to understand the text. Hanley (2017) adds to this and includes *peripheral* developmental dyslexia (refers to letter position, letter identity and visual dyslexia) as well as *central* developmental dyslexia (phonological dyslexia, surface dyslexia and deep dyslexia that affects the later stages of processing). Whilst acknowledging that all are contentious and divisive as little evidence exists for them, Hanley states that research findings confirm three subtypes of dyslexia; namely, *surface dyslexia* (difficulty in reading when pronunciation is not predicted by the spelling), *phonological dyslexia* (difficulty reading and spelling words and non-words) and *letter position dyslexia* (the identity and position of the letters in a word are encoded and read). Contention surrounding what dyslexia is and the different types of dyslexia that are believed to exist, negatively affects the definition of dyslexia.

2.3.3 Defining dyslexia and the debates surrounding it

The definition of dyslexia is a highly contentious issue and cannot be discussed without referring to the debate surrounding this learning challenge. Despite copious research that has taken place into dyslexia, and it becoming more known and not a hidden challenge, the nature and causes remains controversial which leads to its very existence being disputed by a minority (Lawrence, 2009; Macdonald, 2009). The lack of consensus herein has impacted on a single accepted definition of dyslexia with varied definitions in use, which leads to the legitimacy of dyslexia being questioned and doubted by some academics.

Rice and Brooks (2004) view it as an exaggerated learning challenge with a diagnosis that has no scientific basis and thus, differentiating between general reading challenges and dyslexia is not possible. This view is echoed and dwelt on by Julian Elliot, a leading proponent in the criticism of dyslexia, who questions its existence, which he states is based on his years of teaching experience amongst children with learning challenges. His views and writings have resulted in a backlash from many; nevertheless, he is joined by a few researchers in his academic writings. They are however, in the minority when placing their views in the bigger arena of all dyslexia research. Elliot is of the view that without distinct boundaries, dyslexia is a learning challenge that cannot be defined unambiguously as it relies on a number of unsubstantiated assumptions and therefore, it is not a legitimate challenge (Elliot, 2006a). He attempts to validate this view in Elliott and Gibbs (2008, p.476) by stating that dyslexia is a "meaningless" construct with no distinct scientific basis for discerning what a reader or a poor reader is, as opposed to a dyslexic reader, and therefore questions its purpose and educational value. They further state that the educational support and intervention required for those with dyslexia is the same for those with general reading problems. Grigorenko (2001) researched and presented a paper on the role of genes, the brain and environment on developmental dyslexia, and never questioned the existence of dyslexia as a construct. However, her views appear to have changed in that 13 years later she joins Elliot in a paper where the criticism of dyslexia is unrelenting. They state that "understandings of dyslexia are often impoverished, misleading and incorrect" and have little value (Elliot & Grigorenko, 2014, p.580). It appears that the report given by the EU High Level Group of Experts on Literacy (European Commission, 2012, p.30) concurs with Elliot, that readers who do not progress in reading as expected, should not be referred to as dyslexic but the diagnosis should be "struggling reader".

These views are disputed by many including Romberg, Shaywitz and Shaywitz (2016) who firmly believe that the graph of Shaywitz (2012), as shown in Figure 2.3, indicating the discrepancy between the IQ and reading ability of those who are non-impaired, compared to those with dyslexia, provides the evidence of the disparity between these readers. The divergence or gap is much wider between the IQ and reading ability in those with dyslexia, which validates that dyslexia exists and that it is a specific challenge. Of interest is that these authors state that the IQ-reading diverge further validates that those with dyslexia are intelligent.

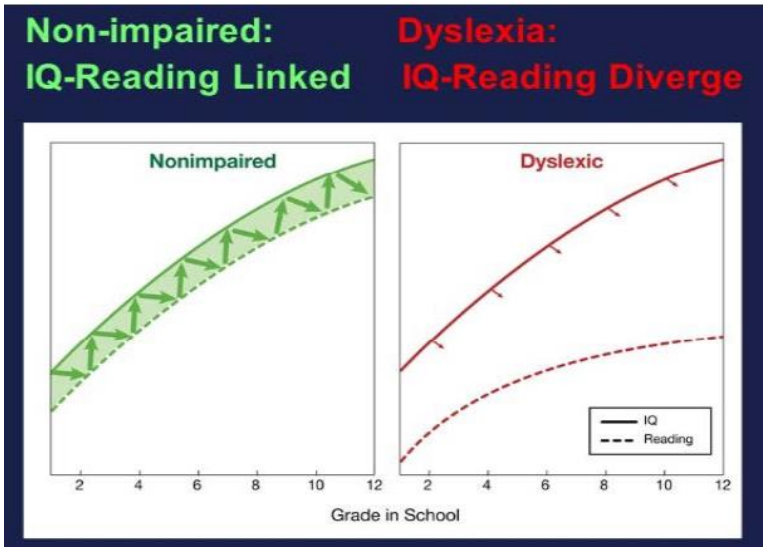


Figure 2.3: Scientific validation of the unexpectedness of dyslexia and thus its existences
(Shaywitz, 2012 depicted in Romberg et al., 2016)

Further possible reasons for the lack of international consensus on the definition of dyslexia, are the multidimensional nature of dyslexia, the different research perspectives used to view it and attempts made to include other specific learning difficulties into a single definition (Lawrence, 2009). Lawrence states that even though dyslexia can be confused with other learning challenges, as there is an overlap with characteristics, there are several important differences, with the predominant one being that dyslexia is a language-based learning challenge. The difficulty with deriving a single accepted definition is further complicated by the fact that the challenges experienced by those identified as dyslexic differ greatly (Taylor et al., 2010), as dyslexia is viewed as situated on a continuum and is not a "have or do-not-have phenomenon" (Troeva, 2015, p.28). Thus, finding a definition that is accepted by all is similar "to finding a needle in a haystack" (Tanner, 2010, p.35).

Several definitions of dyslexia exist which can be problematic for parents and lay persons to understand because of the complexity of the words/terms used. Bornman and Rose (2017, p. 173) state that the definition of dyslexia can be made much simpler for parents by stating that:

> *dyslexia may run in families because there are genetic, environmental and other factors involved. Dyslexia makes it extremely difficult to read, write and spell in your first language – despite having at least average intelligence.*

Parents of children with dyslexia, as well as children and individuals with dyslexia have their own simple definitions and explanations of dyslexia:

- A ten-year-old boy diagnosed with dyslexia defines it as "… when you read to me its fun. I see pictures and understand. But when I read to myself, I am busy trying to read the words and it's no fun" (Gur & Share, 2011, p.108);
- Something that makes my son's brain pathways "not the same as anyone else's … he sees the world a little differently … his brain is different both positively and negatively, and he will use the positive side" (Stringer, Bobrow & Linn, 2011, p124);
- Dyslexia as "an ability disorder in which a child sees letters differently, and mixes them up" (Gyarmathy, 2011, p.154);
- Dyslexia is "a slow learning process in both reading and writing" that will have an influence on life and cause slowness when entering high school (González Seijas, 2011, p.171);
- Dyslexia means "a child cannot read properly" (Inshakova & Arkhipova, 2011, p. 259);
- Dyslexia means that your brain is wired differently and sometimes there is a brick wall that you have to find a way of jumping over or work around (Zambo, 2004).

The definition used by this study, as stated in Chapter 1 (1.4.1 Dyslexia), is that which was adopted in 2002 by the IDA (2017b). With almost every aspect of dyslexia being debated and not having a single accepted definition, it is not surprising that much debate and controversy continues to surround dyslexia.

2.3.4 Possible causes of dyslexia

Despite the extensive research that has taken place into dyslexia since the 1800s, the cause appears to remain unknown and has resulted in many debates and discussions without consensus being reached (Bornman & Rose, 2017; Selikowitz, 2012). Literature reveals that various theories abound, pinpointing the causes of dyslexia, with some researchers indicating the causes being found in the brain or caused by genetics, illness or environmental factors.

In 1925, an American neurologist, Dr Samuel T. Orton stated that reading difficulties are caused by the development of dominance on one side of the brain and he developed teaching strategies for such persons (Selikowitz, 2012). The role of the brain is proven in Shaywitz (2003) where schematic brain activation maps of readers with and without dyslexia showed that during phonological processing, whilst pseudoword (non-word) rhyming, three different systems of the brain of non-dyslexic readers were activated whilst in dyslexic readers little

activity in two systems was seen with increased activity in one system. Hudson et al. (2007) also refers to the role of the brain where the brain activation patterns of readers with and without dyslexia were compared using functional imaging techniques that showed important patterns of differences during tasks that involved sounds in speech and letter sounds in words. Brain scans further revealed that the brain structure of those with dyslexia differed to those without dyslexia in that the left hemisphere language area is less developed, which means that the areas involved in reading and writing do not process information as they should, resulting in the flow of information getting jumbled (Goodwin & Thomson, 2012). However, attributing the cause of dyslexia to the functioning of the brain is not accepted by all.

Selikowitz (2012) and Siegel (2006) dispute the role of the brain by indicating that tests have failed to show that there is direct evidence and state that the causes are unknown. Selikowitz indicates that whilst there is strong evidence that genetics plays a role as is often seen in families, there is no consistency with genetics as it could be inherited from either the mother or the father. Many individuals with dyslexia, interviewed by Anderson and Meier-Hedde (2011) as well as Capellini et al. (2011), had parents, siblings or relatives with dyslexia, thus verifying that it is hereditary and thus runs in families. The role of genes and chromosomes could provide an explanation for the ratio of males to females who are diagnosed with dyslexia, being approximately three to one (Selikowitz). Siegel (2006) states that research identifies chromosomes 6 and 15 as contributing to the cause of dyslexia, but also acknowledges that environmental factors play a role as well.

Peer (2016) has a completely different view and states that dyslexia is caused by the ear, as it is commonly found in children who have had ear infections. Inflammation of the middle ear sometimes causes a fluid build up in the ear resulting in many of the dyslexia characteristics identified in Table 2.1. Research conducted into other possible causes has focused on environmental factors such as a problematic pregnancy, labour, delivery and premature births but findings have shown no consistency (Anderson & Meier-Hedde, 2011). Research reveals that numerous theories abound for the source or origin of dyslexia; however, to date no theory has been fully accepted, therefore the exact cause remains elusive. The following theories and hypotheses, listed in Bornman and Rose (2017) and Peer and Reid (2016), are also viewed as possible causes of dyslexia:

- The Phonological Deficit Hypothesis - The lack of cognitive ability to process sounds in the words (phonemes) despite having normal hearing.

- The Magnocellular Theory - Visual impairments resulting in the images viewed being unstable, blurred and causing eyestrain, as well as possible headaches which affects concentration.
- Cerebellar Theory - A lack of optimal functioning in the cerebellum, which is situated at the back of the brain and responsible for balance, motor control and automaticity.
- Rapid Auditory Processing Hypothesis - Deficits in the perception of short sounds.
- Visual Hypothesis - Visual impairments makes it difficult to process letters and words.
- Perceptual Visual-Noise Exclusion Hypothesis - An impaired ability to filter visual and auditory distractions.
- The Double Deficit Hypothesis - Both phonological and naming of concept speed are contributors.

The various theories have resulted in much debate with many questions being raised. Can it be called dyslexia, or are the challenges the result of a curriculum that is too-fast paced for mastery, a too-generalised curriculum (not all learners learn in the same way and at the same pace), the result of absenteeism and missed learning opportunities or is it the result of behavioural or attention challenges (Armstrong & Squires, 2015)? These authors, however, acknowledge that despite having asked the above questions, it must be acknowledged that there are learners who, in spite of good quality teaching, suitable interventions and a curriculum that is matched to their learning needs, still encounter literacy challenges. This led Rose (2009) to state that this situation can occur and is a reflection of the degree of severity of the dyslexia. Despite the criticism mentioned above, dyslexia as a learning challenge continues to exist for many, and research is pursued in an attempt to gain insight into the many of the unanswered questions.

2.3.5 Characteristics of Persons Experiencing Dyslexia

Research indicates that dyslexia can be extremely complicated as the characteristics and hence challenges faced by individuals are varied, thereby preventing stereo-typing. Alexander-Passe (2015a) refers to it as being dimensional in that there are varying degrees of difficulty with which individuals may experience the challenges ranging from minor to severe. Therefore, no two persons have the same pattern of difficulty (Bell & Tudhope, 2016) as a result of inherited differences in brain development, as well as the type of teaching interventions experienced (Ebere, 2016). This is confirmed in Ingesson (2011) where siblings, diagnosed with dyslexia

differed with their specific challenges. Armstrong and Squires (2015) state that the bio-psycho-social-model as shown in Figure 2.4 provides a possible explanation for the diversity that is seen in those with dyslexia, in that it reflects how the individual's bio-psycho-social dimensions interact, thereby shaping the way in which the individual experiences and presents dyslexia.

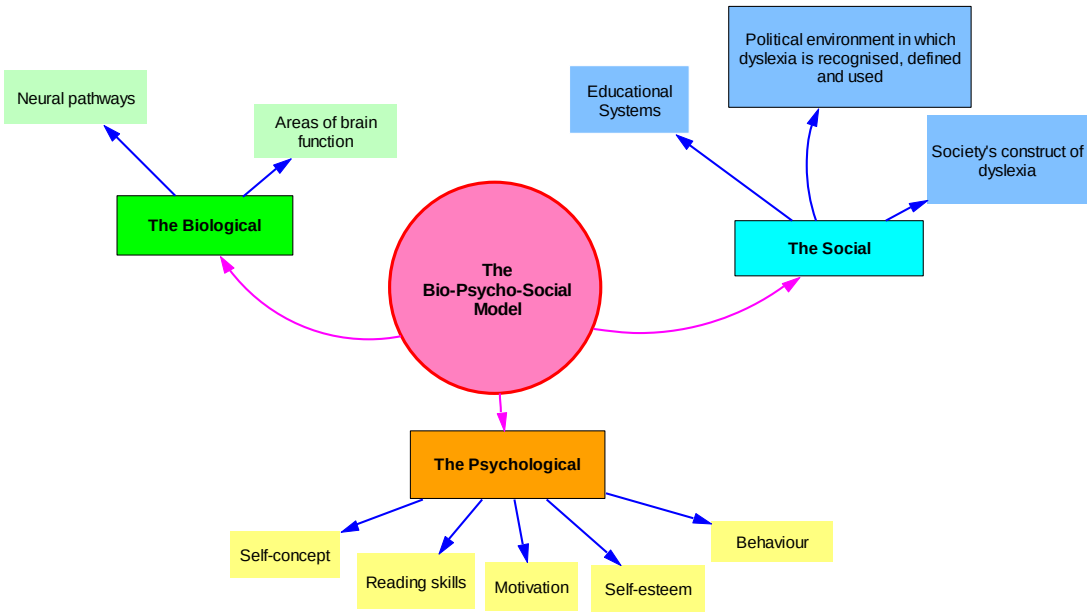


Figure 2.4: **The bio-psycho-social-environment model** (adapted from Armstrong & Squires, 2015)

As a result of this diversity, numerous challenges, both primary and secondary, are possibly faced by those with dyslexia. Whilst challenges with reading are a common feature, Fawcett (2016) states that viewing dyslexia as a reading problem is just one aspect and that it impacts on different areas in the individual's life, a notion acknowledged in Rose (2009). Dyslexia affects concentration and can have secondary effects such as low self-esteem, is multi-faceted, can affect working memory (causes forgetfulness, asks for instructions to be repeated) and contributes to general organisational problems (untidiness) which results in others becoming irritated and impatient (Lawrence, 2009). The possible challenges that can be experienced by those with dyslexia are shown in Table 2.1.

Table 2.1: Characteristics of Dyslexia (Basu, Poonam, & Beniwal, 2014; Bornman & Rose, 2017; Goodwin & Thomson, 2012, Peer, 2016, Selikowitz, 2012)

CHALLENGE	SPECIFIC AREAS OF LEARNING CHALLENGES
Literacy Skills	Reading and Spelling: Learning the letters of the alphabet, slow reading, spelling, spelling words phonetically, spelling a word several different ways, blending letters, reading aloud, confusing letters and numbers that look similar, reversing the order of letters in a word, mapping sounds, comprehension, taking notes, learning sequences (days, months), keeping their reading place, multiplication tables, literacy skills in mathematics (story sums) and subjects that rely on text
Behaviour	Poor attention span, easily distracted, restless, poor organisation, clumsy, lack of self-control, impulsive, differentiating right from left, refusing to do school work, plays truant, day dreaming, difficulty following instructions, withdrawn, feelings of embarrassment, depression, frustrated, ashamed, class clown, aggressive, angry, often cries, tries to avoid work, excessive tiredness from concentration and effort required, headaches, difficulty with multi-tasking, school phobia.
Speech, Hearing and Listening	Speech delays, poor pronunciation, difficulty with direction (right/left; before/after), unable to distinguish sound in words; unable to associate words with correct meanings; unable to sound out the letters in words
Organisational and Motor Skills (includes writing)	Writes too fast or too slow; handwriting untidy/illegible, reverses letters or words, difficulty writing between the lines or colouring in within the lines, work structure problems (where to start), reverses letters or numbers, difficulty copying words, forgets the aim/purpose of the task, poor time management, difficulty following instructions, gross and fine motor skill challenge (clumsiness and coordination), poor grip of pen/pencil
Memory	Remembering instructions, sequences, confusion if given complex instructions, rules, patterns, rote learning, mathematical facts/order/sequences/operations, forgetfulness

Acquiring literacy skills (identified first in Table 2.1) that enable fluent reading and spelling is an ongoing challenge for those with dyslexia, with language playing a role. Whilst some languages are transparent in that every sound is pronounced, English is difficult because the links between the phonemes (units of sound) and graphemes (individual/groups of letters that

makes sounds) are complex (Fawcett, 2016). This complexity is highlighted in Lawrence (2009) where he indicates the process of reading as comprising of:

- A series of complicated sub-skills (recognising letters, knowing letter orientation (b and d);
- Knowing the alphabet;
- Learning phonemes (sounds) and learning digraphs (sounds of letter combinations);
- Followed by the interpretation of letters and words (symbols) together with the comprehension.

Commonly confused numbers and letters by those with dyslexia are '6' and '9', 'p' and 'b' and 'q' and 'd' (Capellini et al., 2011). Compounding the challenges associated with English reading is that it is a language with many spelling inconsistencies (Yule, 2014) as indicated below:

- Enough - where the gh is sounded as an *f*;
- Station - the ti is sounded as an *sh*;
- Heal and health - different sounds for the 'h-e-a-l' part of the words;
- Know and knowledge;
- Fat - where the 'a' has a phonetic sound but the word fate the 'a' changes to the alphabetical name (Armstrong & Squires, 2015).

However, despite the possible challenges faced, individuals with dyslexia are said to think more holistically, are more intuitive and creative with lots of ideas (Goodwin & Thomson, 2012). Bacon and Handley (2014), in comparing the way in which dyslexics and non-dyslexics reasoned, found that those with dyslexia make use of their visual strengths when reasoning, resulting in accuracy. They show strengths in areas that are not based on reading and writing, such as creativity, solving geometrical problems, chess, computers and often have superior verbal skills and skills in building models without relying on manuals (Henry, 2015). Bornman and Rose (2017) concur and state that these individuals excel in what is controlled by the right side of the brain, such as drawing, acting, dancing, verbal communication, athleticism, 3-D visualisation, mechanics, entrepreneurship and intuitive skills. Further proof of this creativity is found in Hickman and Brens (2014), where it is stated that dyslexia is commonly found in art and design students and that a possible reason for this, is a neurological compensation for the dyslexia challenges. Therefore, opportunities to participate in activities in which they excel

must be provided and afforded to them to ensure their success. As shown in Table 2.2 those with dyslexia can be successful despite their dyslexia challenges.

Table 2.2 Famous people with dyslexia (Davis Dyslexia Association International, 2014)

Henry Winkler, Tom Cruise and Whoopi Goldberg	Actors and Actress
John Lennon	Musician
Mahomed Ali	Boxer
Henry Ford, Richard Branson and Steve Jobs	Entrepreneurs
Agatha Christie	Author
Steven Spielberg	Filmmaker/ producer

These famous and successful people with dyslexia proudly reveal their diagnosis of dyslexia. They confirm that whilst dyslexia is never outgrown, those with dyslexia can be taught to negate their challenges and live a productive and happy life. Many of the people named in Table 2.2 have not only achieved personal success but also contribute to society and inspire those with dyslexia by providing their 'stories' in various forums. Unfortunately, no SA names were located to include in this table.

2.3.6 Dyslexia Assessment and Diagnosis

As dyslexia is a learning challenge, it is therefore diagnosed and supported in an educational setting and not in a medical environment (Macdonald, 2013). However, it is important that assessment should be a "process that operates according to scientific principles embedded in clinical practice" with the main aim being to assist the individual (Elbeheri & Everatt, 2016, p51). Therefore, as diagnosing dyslexia is a difficult process (Hudson et al., 2007), it should never be made by the class teachers or by parents, as they lack the training to carry out a comprehensive assessment (Selikowitz, 2012). Literature reveals that teachers with no training in making the diagnosis are doing so and thus labelling learners (The Secret Teacher, 2015; Tshililo, 2016).

Teacher assessment or identification of dyslexia as in Tshililo (2016) has implications at several levels, of which the main problem is that teachers lack the knowledge to carry out the tests and use the tools for assessing learners with dyslexia (Armstrong & Squires, 2015). It is therefore imperative that assessment is carried out by a trained professional as several specific learning difficulties such as ADHD, Autism and Asperger's syndrome can be confused with

dyslexia as a result of an overlap in characteristics (Lawrence, 2009). Snowling (2012) and Rose (2009) concur and state that co-morbidity makes diagnosing dyslexia difficult, therefore due to its complexity, assessment should only be done by psychologists or specialist dyslexic teachers with qualifying certificates. This leads Asghar et al. (2018, p.1) to distinguishing the diagnosis made by trained and qualified professionals as an "expert-confirmed diagnosis".

Various professionals are identified as being the persons to make the diagnosis with a slight variation globally. In some countries, a speech and language therapist conducts the assessment, in others an educational psychologist or a team of professionals (Anderson & Meier-Hedde, 2011). Not all researchers share this view of assessment being carried out by these particular professionals only. Selikowitz (2012) states that an educational psychologist and a paediatrician should work closely together with speech therapists, physiotherapists and occupational therapists, and they should coordinate with each other to establish the nature and causes of the learners' challenges. Findings during my master's research revealed that assessments carried out within the South African education system or scheduled privately by parents, and accepted as authentic, are done by a registered clinical, counselling or educational psychologist (Hoskins, 2015).

The actual tests used to assess dyslexia are surrounded in controversy and debate as there is no single recognised and acceptable test used by all. This is referred to in Lyon, Shaywitz and Shaywitz (2003), where they acknowledge that whilst various tests are used to identify dyslexia, it is important to take cognisance that there is no single dyslexia test. This is evident in the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association (APA). This manual contains descriptions, symptoms, and criteria for diagnosing mental disorders and is used by health care professionals in many parts of the world, including SA. Criterion used for the assessment of dyslexia suggested in the DSM-IV differs from that suggested in the DSM-V. The DSM-IV makes use of discrepancy criteria wherein the discrepancy between intelligence versus reading and writing ability is used to denote the specific reading and writing challenges (Ingesson, 2007). This has changed in the DSM-V which eliminates the "Discrepancy Criterion", and places emphasis on "Response to Intervention" approach which groups together learning disorders within the Neurodevelopment disorder group, with the word dyslexia only being used in the clinical field (Petretto & Masala, 2017, p.1). De Jong and van Bergen (2017) believe that diagnosing dyslexia should be an interactive process where the first step is the assessment of the reading and spelling challenges

and the second step revolves around examining exclusion criteria. Whichever criterion are used, it is important that assessment of an individual must be accompanied by an awareness of their linguistic, cultural and background elements which should form a framework for the assessment and part of the exclusion criteria (Elbeheri & Everatt, 2016). It is imperative that assessments must be ethically sound and in the case of a child, be done with the consent of both the parents and the child (Armstrong & Squires, 2015). Assessments can be arranged with the appropriate professionals by schools via the education department, or by paediatricians and psychologists in private practice (parents initiate this). In SA as a result of the shortage of school psychologists, such assessments are often carried out privately and thus paid for by the parents.

2.3.6.1 Dyslexia Assessment Process

Literacy challenges in learners are usually noticed first by the teacher (Troeva, 2016) who compares the competency in academic skills and behaviour with that of peers (Selikowitz, 2012). This is however, disputed as it is indicated that it is often first identified by parents, especially mothers who notice their child's literacy struggles and often they are turned away, belittled or ignored by teachers who provide their personal misunderstood reasons for the learner challenges (Anderson & Meier-Hedde, 2011; Earey, 2013; Heimdahl Mattson & Roll-Pettersson; 2007; Yildiz, Yildirim, Ates & Rasinski, 2012). Rose (2009) agreeing with Troeva (2016) states that the procedure followed often starts with the class teacher who identifies the literacy problems and refers the learner to a specialist dyslexia teacher/experienced literacy teacher to assess the learner's challenges and make the diagnosis in consultation with the parents. Boyle (2014) indicates that teachers refer the learner to an educational or school psychologist who is the main referral point in the system to make the diagnosis, then label and hence categorise the learner.

Assessment should be carried out in four stages after vision and hearing tests have been conducted, namely the collection of information about the child, testing by a psychologist using various tests, an explanation of findings to parents and finally, recommendations of an appropriate management plan if a positive diagnosis is made (Selikowitz, 2012). Participants in Higgins et al. (2002) refer to the enormity of the assessment process involved in achieving accurate labelling and indicate it as being a challenging time in facing the medical assessments (eye and hearing tests), as well as the questioning and literacy tests.

Factors contributing to the awareness and/or assessment of dyslexia in adults and children differ greatly. Dyslexia is viewed as difficult to detect in adults because of them appearing to cope, resulting from having lived with dyslexia much longer and possibly never knowing about it or seeking a diagnosis (Goodwin & Thomson, 2012). Adults often discover that they could possibly be dyslexic as a result of:

- A school or college teacher or a member of the family suggesting it;
- Their child might be assessed and the parents recognising that they have the same challenges;
- Someone in the workplace suggesting it; or
- A news item describing dyslexia makes the adult aware that they have those challenges (Troeva, 2016).

This is verified in Grimes (2009), where a parent who was a school teacher discovered on the advice of a colleague that her son could possibly be dyslexic, and then realised that dyslexia was the cause of not only her learning challenges but also the challenges faced by her dad and aunt. This parent attributes her success in life as stemming from the acceptance and support she received from her family, having positive role models, her self-esteem, as well as achieving academic success and support that came from interested and helpful teachers.

2.3.6.2 Should diagnoses occur?

Controversy surrounding an accepted definition has resulted in dyslexia being misunderstood, resulting in low identification rates whilst in school, and many are only diagnosed in adulthood. Added to the complexity of the debate are the social, cultural and philosophical issues that surround the purpose of assessment (Armstrong & Squires, 2015; Higgins, Raskind, Goldberg & Herman, 2002). There are thus differing views on whether assessment should occur and various reasons given for and against. However, the findings of research and the views of those with dyslexia appear to favour assessment and hence diagnosis.

A lack of diagnosis has negatively impacted the lives of thousands of children and adults who have not been identified as dyslexic, resulting in them living with feelings of unexplained failure and low self-esteem (Peer & Reid, 2016). Failure to diagnose dyslexia has a negative impact on academic achievement, which is emphasised and seen as an indication of success in many societies and cultures (Bell & Tudhope, 2016). Diagnosis provides an understanding to the learners, parents and teachers, thereby reducing the negative or mysterious feelings that are

associated with the inabilities (Hudson et al., 2007) and provides a sense of relief as they no longer have to wonder what is wrong with them (Stampoltzis & Polychronopoulou, 2009). Damico, Müller and Ball (2013) state that the accurate diagnosis of a learning challenge could result in positive psychological and social consequences as it will create an understanding of the challenges faced as well as the action or a programme devised to assist. In the UK, identifying learners whilst at school is seen to be the statutory duty of the school and in 2008, parents sued their local council for failure to diagnose their child and won the case, resulting in being compensated (Lipsett, 2008).

Loveland-Armour (2017) reveals that whilst a large majority of learners are not identified at school, diagnosis sometimes occurs when they are older and whilst studying at university. This finding is confirmed in Gibson and Kendall (2010) where participants revealed the anxiety experienced as a result of not being diagnosed. They disclosed their struggles faced through school and feeling like they were stupid, with relief and answers provided about their challenges only occurring whilst at university when a diagnosis was made. A participant in Shaw, Grant and Anderson (2017) indicated that only being diagnosed in his second year at university permanently lowered his graduation ranking and employment opportunities. However, it is important to note that early identification of dyslexia is almost meaningless if it is not followed with the necessary support.

Support is best if it is provided in the early years of a child's life, as it can significantly improve both reading and writing; have a lasting impact thus preventing failure and unnecessary stress (Fawcett, 2016). Such support could be through the implementation of suitable educational plans to enhance success, and accommodations that can be put in place such as alternative testing methods, computers and taped books (Ho, 2004). Anderson and Meier-Hedde (2011) concur and indicate that diagnosis must be followed with a specialised remedial reading programme that ensures that the learning challenges experienced can be lessened and good academic progress made where the gap between the reading level and grade level is reduced. The value of diagnosis is however, not only confined to learners but is of value to adults as well.

McLoughlin, Leather and Stringer (2002) state that adults with dyslexia in the workplace might find themselves in a situation where they are unable to function optimally because even though they are unaware of their dyslexia, they have developed skills and strategies to overcome it,

with or without a good understanding of how they accomplished this. Some adults with dyslexia in the workplace might be aware of their dyslexia yet they have not developed such skills and strategies. They further state that optimum functioning in the workplace for those with dyslexia is achieved when they are aware, have an understanding of their challenges and have been equipped to work with it and overcome it.

2.3.7 Interventions for those with dyslexia

Diagnosis of dyslexia has little value if appropriate interventions are not put in place, as these are of paramount importance for success, especially in acquiring the necessary literacy skills that dominates most areas of life Rose (2009). Learning to read is a skill that can be accomplished by those with dyslexia as confirmed by Ford (1928). This is verified in the Literacy Report of the European Commission (2012) wherein it is stated that most people can be taught to read and have the potential to become good and even excellent readers, if they are provided with specialist support. This Commission further states that failure by the education system to teach those with dyslexia how to read, will negatively impact on society, as such persons will be unable to make the contributions that they are capable of making and which society needs. Without appropriate intervention to assist them to read those with dyslexia will be academically, socially, emotionally and economically vulnerable (Hurford et al., 2016; Zambo, 2004), which impacts greatly on their being throughout life. Dyslexia therefore goes beyond education to affect everyday living and possibly has an effect on the individual's job or career.

Romberg et al. (2016, p.976) strongly believes that the starting point of addressing dyslexia is to understand dyslexia and that there is a difference between dyslexia and learning disabilities. These authors indicate that it is of vital importance that dyslexia is viewed as a "highly specific condition" whereas learning disabilities refers to a "general nonspecific category". Global case studies however, reflect that many schools and teachers see dyslexia as non-existent, or it is never mentioned and teachers often blame learning failures encountered as a result of dyslexia, as being caused by such learners being lazy and/or slow to understand or on parents for being neglectful or overprotective (Anderson & Meier-Hedde, 2011). Such attitudes places those with dyslexia at a great disadvantage for the rest of their lives, as it is of vital importance that assistance should be given whilst such learners are at school (Gyarmathy, 2011). Research points to intensive and consistent remedial intervention needed for learners with dyslexia to make progress, and that if schools are unable to do this or fail to do this, the possibility of

success for such learners is negligible (González Seijas, 2011). Educating those with dyslexia demands "high-quality teaching" for good academic progress to be made and focus should not only be on the "multi-sensory or phonemic awareness programmes" but should revolve around the "needs of the whole child" (Burden & Burdett, 2005, p.103).

Learners with dyslexia can learn to read both accurately and at an acceptable level of fluency by the end of the first or second year at school, if they receive the appropriate remedial support (Skaloumbakas, 2011). Lyon et al. (2001, p.269) questions the harsh reality of not providing this support timeously by stating that "children who get off to a poor start in reading rarely catch up". Fairbanks (1992) is of the view that teachers are too preoccupied with students' inabilities and fail to notice their strengths. However, as indicated in Williams and Lynch (2010), teachers lack knowledge of dyslexia as it is not found or addressed in the curriculum of teacher preparation programmes. Globally more should be done, such as policy development for early diagnosis, improving teacher training programmes and special teacher preparation programmes to enhance a greater teacher understanding and thus equip teachers to provide these learners with the teaching that they need (Anderson & Meier-Hedde, 2011). Teacher ignorance in dyslexia appears to be immense, therefore addressing their training is of vital importance for the benefit of these learners (Earey, 2013).

However, Camp and Aldridge (2007) are of the view that teachers should not sit back and wait for information on dyslexia to be given to them. They state that teachers should become "consumers and producers of education research', they should seek such information themselves through various associations and work for the rights of these learners through such organisations. Anderson and Meier-Hedde (2011) further state that it is important for teachers to understand the role that technology can play in assisting such learners so that progression through the school system can take place and these learners can gain academically, psychologically and socially.

Intervention however, should not result in providing limited opportunity or seeing the learner as being inept. If this occurs, learned helplessness is often exhibited by those with dyslexia or when too much support is given, it results in them being less challenged. A degree of learned helplessness (learned dependency) is developed wherein learners overly rely on support, will not attempt tasks within their competency on their own, appear to give up, which reduces their ability to learn and solve problems (Armstrong & Squires, 2015). Bornman and Rose (2017)

refer to learned helplessness as the worst challenge of all and state that it stems from low expectations for the individual and others thinking that they are unable to do certain things independently, so they do it for them or assist them. This clearly shows that the learning challenge is not fully understood and also possibly caused by the lack of the specific label. Interventions are a prerequisite for those with dyslexia to reach their full potential. Interventions include assessment together with counselling to ensure both a self-understanding (the nature of the challenge, what can be done about it and one's strengths) and an understanding for others involved in the person's life thus enabling optimal functioning in learning, in work places and in social settings (McLoughlin et al., 2002). They further indicate that assistance in leading them to develop their skills is essential as well as accommodating and making compensations for them to achieve.

Without intervention, children and adults worldwide are at risk of experiencing lifelong illiteracy as well as social exclusion (Dyslexia International, 2014). This aligns with Carawan, Nalavany and Jenkins (2016) that dyslexia in late adulthood poses a risk factor for a well-lived life and this can be due to adults being unable to develop successful coping and adaptive strategies and thus living with insurmountable challenges. Therefore, early diagnosis and appropriate intervention negates this risk. Such learners can achieve both academic and personal goals set provided that their needs are recognised and they are given appropriately support by all in the school (Exley, 2004).

2.3.8 The term and label of dyslexia in the 21st Century

Lawrence (2009) is of the view that research into dyslexia, when compared to other topics in psychology is still in its early stages and many unanswered questions remain, with statements sometimes made without the basis of scientific evidence. This could contribute to the controversy surrounding the definition, existence and labelling of dyslexia including the use of the word 'dyslexia'. Literature, as discussed hereunder, shows that even though the symptoms of dyslexia are listed as challenges, the word dyslexia to describe these symptoms is evaded under the premise that not all literacy challenges are dyslexia. Thus, there is sometimes a complete avoidance of the use of the word as well as avoidance of the term in schools.

Thomson (2012) states that there will always be individuals with disabilities, therefore there will always be labels, and pretending that disabilities are non-existent, results in a heightening of stigma attached to it. This view is echoed by Kauffman (2003) who states that there has to

be a willingness to talk about disabilities openly so as to address the problem of the stigma that accompanies it. Is this openness found in Landsberg (2011), who offers a SA perspective on addressing barriers to learning, and makes no mention of the word dyslexia? Whilst this could be as a result of being influenced by either the social and positive theoretical models, it is not however, in complete keeping with the EWP6 that provides an outline for an inclusive education system. This EWP6 states that it will "retain the internationally acceptable terms of 'disability' and 'impairments' when referring specifically to those learners whose barriers to learning and development are rooted in organic/medical causes" (DoE, 2001, p.12). Landsberg (2011) does however, list characteristics of dyslexia on pages 402-404 under the section in which learning impairments (a broad/general label) is discussed and this is followed with a section on Attention Deficit Hyperactivity Disorder (ADHD), which she obviously recognises as a specific barrier to learning. This leaves me pondering why the word 'dyslexia' is shied away from and why the specific label is not used? This despite the fact that dyslexia and ADD are stated as being two of the most common learning disabilities diagnosed in both children and adults (Claassens, 2007). Decisions are made in the educational system based on presuppositions which are accepted as universal (Markham, 2005). This leads me to question if the view of the South African Education Department and the choice of academia to not use the word 'dyslexia' is validated by those diagnosed with it? Markham states that it is imperative that such presuppositions are examined to ensure that it is in the best interest of the learner.

Similarly the American Psychiatric Association (2013) in the updated Diagnostic and Statistical Manual of Mental Disorders referred to as DSM-5 makes no reference to dyslexia in its index. Dyslexia is however, briefly mentioned under the section of Specific Learning Disorder (SLD) wherein it states that "Dyslexia is an alternative term used to refer to a pattern of learning difficulties characterised by problems with accurate or fluent word recognition, poor decoding and poor spelling abilities" and that if these difficulties are referred to as dyslexia then it is "important to specify any additional difficulties that are present such as difficulties with reading comprehension or maths reasoning" (American Psychiatric Association, 2013, p.67). The DSM-5, unlike the earlier version namely the DSM-4, groups all the learning disorders into one category namely SLD and the term dyslexia is only suggested in the clinical field (Petretto & Masala, 2017). Selikowitz (2012, p.4) states that SLD, as referred to in the DSM-5, covers a group of disorders and defines SLD as an "unexplained condition, occurring in a child of average or above average intelligence, characterised by a significant delay in one or more areas of learning".

Bishop (2014) is of the view that the current situation with diagnostic labels, as seen in the DSM-5 which gives broad terms, namely SLI (Specific Language Impairment) that identifies a wide range of conditions, causes confusion, impedes progress in research and denies individual's access to appropriate services. Bishop further states that precise labels are needed as broad labels could have serious negative consequences for the individual if it results in failure to address the impairment. Boyle (2014) concurs with this view and states that SLD outside of education is not clear and could lead to confusion, whereas the label of dyslexia is recognised and understood by most as indicating a difficulty of reading. Clark and Carter (2014) are of the view that the broad term used in the DSM-5, namely SLI, falls short based on the fact that there are a wide variety of labels used for SLI both in literature and in practice. Strudwick and Bauer (2014, p.413) criticise the broad term used in the DSM-5 and are of the view that in order to provide what is appropriate a clear understanding of the precise need is required. They further state that "a label will only be as good as its meaning; otherwise it becomes packaging rather than the contents".

Much variance is found in the use of the terms 'learning disability', 'learning difficulties' and 'barriers to learning' with all three referring to challenges experienced by learners. Different countries as well as various institutions embrace one of the above-mentioned terms. Lloyd, Keller and Hung (2007) state that learning disabilities (LD) was a concept that arose in the 1960s in the United States when the first paper on it was published by Samuel Kirk and Barbara Bateman in 1962, leading to the birth of this concept. They further state that this concept embraced by countries such as Botswana, South Korea, Guatemala, Israel, Norway, Portugal Spain and Taiwan, has remained unchanged with it still referring to the academic challenges that some face, despite them not having other disabilities such as "sensory impairments, mental retardation or emotional and behavioural disorders" (p.159).

The EWP6 (DoE, 2001, p.12) adopted the use of the term "barriers to learning and development" which is used to replace "learners with learning difficulties" and "learners with special education needs". This term is used broadly without naming specific barriers. Boyle (2014) states that despite the variation in the term used, a label has been given to the individual - which is what is trying to be avoided. Therefore, it shows that labels, general or specific, cannot be avoided. The EWP6 states that barriers to learning can be as a result of the innate challenges experienced by the learner or as a result of the barriers to learning existing in the educational and training system, by not providing for the educational needs of these learners.

This is in keeping with the social model of disability (ways in which society can assist) as well as with positive psychology, which believes that the language used has an effect on reactions and views. Lawrence (2009) states that dyslexia is now formally recognised in educational circles; however, the researcher during research conducted for a master's degree, found that this recognition does not exist in SA educational circles.

Whilst the IDA, which is based in the USA, together with its affiliates uses the term learning disability in their reference and definition of dyslexia, various centres worldwide who offer assistance with the teaching of dyslexia, refer to it either as a learning disability or a learning difficulty. The researcher, while acknowledging the terms 'learning disability', 'learning difficulties' and 'barriers to learning' as constructs in this study embracing dyslexia, views the term 'disability' as negative and equating with the medical model or deficit model, which sees the word as suggesting or alluding to a deficiency within the person. This view concurs with Zembylas and Isenbarger (2002), who state that the label of learning disabled is negative in that the student is viewed as disabled rather than differently abled or capable and thus, this term gives schools a negative image of the child's abilities. The question asked is whether this controversy on the correct term is having a ripple effect thereby impacting on the individual being diagnosed, on diagnoses and the lens through which the person sees and is being seen.

Whilst third parties indicate their views and preferences of which terms to use, adults with dyslexia, interviewed in McLoughlin et al. (2002) reject generic terms such as 'learning difficulties' or 'learning challenges' being used instead of the word 'dyslexia'. They consider such terms to be inappropriate and demeaning in that a literacy challenge does not mean that they have learning difficulties, but simply means that they learn differently and therefore can learn. Fawcett (2016) concurs with this view by emphasising that dyslexia is a difference in learning, and not a reading deficit.

Irrespective of the term used, Troeva (2016, p.381) views dyslexia as a "signpost" that indicates that there is a need and indication that a differentiated approach, together with a focused intervention is needed for teaching the skill of reading to learners with dyslexia. Camp and Aldridge (2007, p.10) firmly believe that it is imperative that all involved need to "move education beyond antiquated 1970 reading practices into a more enlightened and humane 21st century" for the good of such students/learners. The need to do so is found in the words of Winkler (Zipzer, 2007, p.64) where he states "so we learn differently- it does not mean that

you will not meet you destiny or you will not achieve success". Those with dyslexia can learn and be successful. Lawrence (2009) and Rose (2009) stress that there are no limits to what can be achieved by those with dyslexia if they receive appropriate intervention. A lack of such intervention robs those with dyslexia in many ways, but can appropriate support be provided if the very core of dyslexia, namely the definition is surrounded by debate and controversy?

2.4 LABELLING

My review of research undertaken thus far in the field of labelling has been of great value and has impacted on me as a researcher in various ways. It has widened my knowledge base and made me realise, even more than when I started this research that the topic of labelling is a sensitive issue. My personal bias, stated in Chapter 1, has decreased, as I acknowledge that I too am a secondary person who is not personally experiencing living with the label of dyslexia, therefore the choices are not mine to make on behalf of others. However, this literature review has validated that this topic was in dire need of research, especially using the perspective of the diagnosed person. As a result of the gap found in literature regarding the labelling of those with dyslexia, this section of the literature review is therefore not solely confined to the specific labelling of those with dyslexia, but also includes the general labelling of those with a learning challenge.

We live in a world of labels that are given almost from conception to birth and throughout life, by both professional and nonprofessional persons. Labelling of persons or objects is therefore a universal phenomenon that is inherent to life. People have however, made the choices of which labels are acceptable or unacceptable, and often these choices are made on behalf of others and not by the persons themselves. People have also chosen the language of the label and how to interpret it thus impacting on how the label is experienced and reacted to (Markham, 2005). This validates the view of Damico et al. (2013) that although labels are historically and culturally situated and seen as being specific and fixed, they are actually fluid and subjective.

Literature reveals that the labelling of a learning disability is a topic that has been debated extensively on many grounds and predominantly by third parties with many views expressed, validated and held. It has been researched in the educational, psychological, medical and social spheres for many years. Political, psychological and ideological uncertainties are therefore all viewed as contributing to the challenges and debate of labelling (Arishi et al., 2017). Despite this debate and weighing up the pros and cons of labelling, Boyle (2014) stated that the

labelling of individuals regardless of whether it assists or not, is inevitable and therefore a part of life. It however, must be acknowledged that labels have a powerful lifelong influence on the way in which individuals are perceived and judged with stereotyping and assumptions often resulting for those who share the same label (Foroni & Rothbart, 2013). In looking at the power of the influence of the label and the debate of labelling, I ponder whether the label is a lifelong unnecessary burden for the individual, querying whether the lack of a label increases negativity to the person's challenges as a result of ignorance or whether the label provides an understanding of the challenges faced by the person, resulting in acceptance and positivity.

Macdonald (2009) is of the view that the label has little value and is counter-productive if it takes place to just provide a label without providing additional support. The decision of whether to label or not, according to Lauchlan and Boyle (2014), appears to have a simple answer to settle the debate. If an affirmative answer is given to the question of whether the label can positively change the challenges of these learners, then it leaves no room for argument against the use of labels; however, if the answer is conveyed without absolute positivity, then the attachment of labels to individuals must be cautiously approached. Despite this apparent simple solution, research into the pros and cons of labelling continues.

2.4.1 What is labelling?

Damico et al. (2013) views labelling as a complex sociocultural artefact that is not direct, simple or objective, and a catalyst for both positive and negative consequences, by transmitting biases, assumptions and even facts. Gold and Richards (2012, p.144) describe labels as "the assignment of a descriptor to an individual, based on selected behavioural and/or physical characteristics" that "places the individual into a specified group possessing similar characteristics". Arishi et al. (2017) concur and state that a label is often viewed as an indicator of the value and place in society assigned to the individual as a result of possessing the characteristics of the label. Therefore, labels are in effect public announcements (Thomson, 2012) and are therefore not private and solely confined to the individual, but extend to society. It goes beyond the home and education, and follows the person into the adult world, into the workplace and hence into the community and society. Society plays both a judgemental and influential role in the life of the labelled person. Its influence, direct and indirect, is found in both education and medicine where it makes a significant contribution to decisions made (Algraigray & Boyle, 2017).

Becker's 1963 labelling theory refers to the role played by societies in what is regarded as accepted norms (Becker, 1963). According to this theory, norms, differences and rules as established by society or the community, and those who do not fit in or deviate, are ostracised resulting in the labelled individual experiencing discrimination and sometimes also abuse (Algraigray & Boyle, 2017). Society or the community dictates what is acceptable or not acceptable by judging the divergence from norms. The labelled person is assigned a new identity by society, who sees the individual as having a new role and the expectations for the individual changes once a label is assigned (Osterholm et al., 2007). This is verified by Arishi et al. (2017) where it is stated that sometimes the person's identity is confined to that of being a dyslexic person. It could lead to the individual believing that they are the label resulting in a negative effect on self-image and hence self-esteem (Gold & Richards, 2012). As a result of society's treatment of the labelled person and their supposed deviance from what is accepted as the norm, the deviation increases and the person is viewed as being no greater or able than the disability (DeRoche, 2015). Algraigray and Boyle (2017) therefore view labels and classifications created by both the education system and medical industry as being socially developed to carry meanings that lead to the devaluation of persons being labelled, which reduces their ability to be fully valued by society and recognised as equals.

Social judgements and perceptions made of such individuals (Hunt, 2006) often result in them having a negative persona. Societies judgements are reflected in Lisle and Wade (2013) where individuals with the label are stereotyped and viewed as being less attractive, achieving less success in future life and being less emotionally stable. They state that these judgements result in a perpetual cycle of bias towards those with the label, which results in continuous struggles for the labelled person. As a result of society's role, Arishi et al. (2017) state that the labelled individual continuously monitors his/her socio-cultural environment looking for cues regarding acceptance or rejection by others. Markham (2005) states that this rejection is caused by society's presuppositions of labels and the language used, which results in stigma and hence ignorance that is attached to labels. In doing so, little consideration is given to the personal effects that such judgements have or to the damage that they cause to an individual's sense of belonging and fitting in. DeRoche (2015) states that the damage is seen in the three secondary effects triggered by the label, namely being socially stigmatised, being excluded from various social opportunities which includes interacting with peers and employment opportunities, and the third is the internalisation of the negative labels. Macdonald (2013) states that it is regrettable that current research and debates on the labelling of individuals with dyslexia

focuses on the stigma or legitimacy of labelling and excludes the concept of social identity that results from the label, as this could enhance our understanding of the dyslexia identity.

The social stigma of having a learning disability label, which some see as referring to below average intelligence, is a concern for both learners and adults, including the role players in their lives, and society must to be made aware of the lifelong damage that this causes the individual (Boyle, 2014). As a result of experiencing social stigma, the participants in Taylor et al. (2010) viewed the private use of the label more positively than negatively, in that it assisted those close to the labelled individual to understand the challenges faced and led to them being assisted with their challenges. However, they indicated that the public use of the label led to stigmatisation, bullying, ridicule and caused teachers to isolate them from their peers. Romberg et al. (2016) view ignorance and misperception as being the major cause of bias that is shown towards students with dyslexia.

Scior et al. (2013) examined the effects that labels have on lay person's beliefs, emotional reactions and where it places the person in society. They state that even though labels are opposed by the disability rights movement, the use of diagnostic labels can actually reduce society's stigmas towards the person, by preventing the misunderstanding for the reasons why the challenges are faced. Educating people is therefore of utmost importance to create awareness and understanding. Lawrence (2009) strongly advocates the need for public education programmes to increase awareness and understanding in society about dyslexia. Goodwin and Thomson (2012) view this as already taking place with people becoming more aware of dyslexia as a result of television and radio programmes, as well as the written media. However, adults in Alexander-Passe (2015b) feel that more public awareness and knowledge in dyslexia is needed as this will reduce the negativity with which dyslexia is viewed, and lessen the discrimination experienced from peers and in the workplace. Ho (2004, p.87) is of the view that irrespective of the debates and educating people about learning disabilities, labels indicate that the person is different, resulting in them always being viewed as being inferior and not fitting into what is regarded as the 'normal population' thereby frequently creating social disadvantages for the labelled person. However, this research is of the view that educating society about dyslexia appears to be imperative and could save many the pain and anguish caused by ignorance, especially in light of dyslexia being referred to as the most common learning disability (Allen, 2010; Van der Leij, 2013).

2.4.2 Labels for those with dyslexia

Whilst some researchers are opposed to labelling but not to diagnosing, some do not believe in the existence of dyslexia thus impacting on their views of the label and labelling. Elliot (2006) states that the label of dyslexia is nothing more than a means to provide a positive self-construct for both the individuals and their parents and is also a means of obtaining educational resources for such individuals. Possibly concurring with Elliot (2006), Levine, a paediatrician and child-development expert does not only dispute dyslexia but also the existence of learning disabilities and insists that learning is different for all (Ruenzel, 2001). He believes that teachers should rather attempt to understand the brain's complexity and to possibly dissect student learning difficulties which will enable them to look into the neurocognitive profile of the learner without being judgemental. Elliot and Grigorenko (2014) believe that the label of dyslexia continues to exist because it meets the social, political and emotional needs of various parties. Elliott and Gibbs (2008) reiterate that the word dyslexia and hence the label, is a puzzling and complex construct and that the label is unhelpful to teachers as there is no evidence that particular approaches are more appropriate for learners with supposed dyslexia than for others with literacy challenges. They further suggest that the label of dyslexia is unhelpful to the individual's well-being and progress in education. This view is possibly in line with the SA education system, which distances itself from using diagnostic labels and prefers the use of general labels.

Hegstad (2017) is of the view that labels in life are inevitable and that a person with dyslexia lives with one of three labels; namely, dyslexia, special educational needs (SEN) or no label. Using the specific label of dyslexia instead of the general SEN label appeared to be favoured by the participants in Hegstad's study, where they indicated that not using the specific label of dyslexia often resulted in other derogatory labels being used such as dumb, incompetent or lazy. Taylor et al. (2010) indicate that this is possibly caused by the SEN label not providing an explanation for the specific academic challenges faced, as well as the lack of a targeted intervention. This concurs with Riddick (2000) who found that the specific dyslexia label was preferred to previous labels such as dumb and lazy given by parents, teachers and peers. Armstrong and Squires (2015) are of the view that the specific label of dyslexia provides an explanation for the challenges that the individual faces, therefore appeasing the learners, parents and teachers, whilst the term/label 'slow reader' or 'poor speller' is viewed negatively. This reasoning is assigned to the medical sounding name being more valued than the ordinary description. Lawrence (2009) also advocates the use of the specific label of dyslexia and views

it as being useful, not a handicap. He attributes present day recognition and acceptance of this label as being the result of the dedication and perseverance of parents who fight for this awareness, so that the needs of such learners are acknowledged and improved. However, in Spain the word dyslexia is not used as it is believed that nothing can be done to assist or help such individuals, whereas if the need is SEN they are protected by the Organic Law of Education, which stipulates that schools have to provide tutors for such learners (González Seijas, 2011).

It is apparent that some labels appear to be more acceptable than others. Hunt (2006) states that familiarity with the label plays an important role with how the label is viewed and accepted. Hunt provides an example in the viewing of ADHD and dyslexia where, as a result of medication being available that can assist those with ADHD, dyslexia is seen as being more debilitating. In viewing the label of dyslexia, Macdonald (2013) states that psychology and education shapes our understanding and whilst such labelling is viewed as either being positive or negative, it must be acknowledged that labelling has both positive and negative outcomes. Such outcomes could be the effect that it has on the attitudes of the family, teachers and society, as well as the possible effects that it might have on the various psychological and social aspects of the individual with all having a contagion effect.

2.4.3 Advantages of labelling

Research shows that there are both direct and indirect advantages in the use of labels for individuals. Labels are viewed as necessary and important as they provide reference to a particular need, provide the foundation for provision and intervention, and impart an understanding of the challenges faced (Bishop, 2014). Therefore removal of labels will be detrimental as it could lead to the removal of support for many challenged learners (Bishop).This is validated in Wearmouth (2004) where incorrect provisions were given to a learner causing much frustration and unhappiness. It was only after diagnosis and being labelled, that the appropriate interventions were provided resulting in academic achievement. This is also reflected in the study of Anderson and Meier-Hedde (2011) where reading remediation provided prior to being diagnosed had little impact on a learner's challenges, which actually increased in severity. Clark and Carter (2014) state that the advantages of labelling was seen amongst the teenagers and adults with whom they worked. Not having a label, disempowered these individuals, created anxiety as they did not understand the nature of their difficulty and they believed the negative terms used by their peers and others.

The advantages of labelling are also seen in the educational arena. Kivi (2015) states that the positive effects of labelling for teachers is that with the knowledge of learner challenges and needs, educational plans can be developed wherein extra learning support is offered and specialised education is provided to enable them to succeed. However, such plans should never denigrate these learners by segregating them and making all in the class aware that they are different as this could lead to embarrassment, fearfulness and negatively, which will have a negative affect (Savaria et al., 2011). Markham (2005) states that as an teacher, she was unaware that the language of the label had an effect on the way in which she regarded such learners and that once she changed her language and saw the label not as 'learning disabled' but as indicating that the bearer of the label learns differently, her bias towards the learner diminished and she now believes that the label is beneficial.

Kivi (2015) and Macdonald (2009) state that learners with learning needs must be identified and labelled to provide them with not only the educational tools but also with the emotional tools that will assist and enhance success. The consequences of being a learner and not having the label is expressed in Gibson and Kendall (2010), where participants revealed that it resulted in feelings of failure throughout their school tenure. They viewed the label as providing an explanation which results in an increase in self-confidence and determination to succeed. Alexander-Passe (2015b) states that whilst labels are only as valuable as the intervention that results from the diagnosis in education, the lack of labels could prevent teachers from knowing the strengths and weaknesses of their learners. Baird (2014) is of the view that many who are not in favour of labelling, often base their views on the diagnostic classification of learning disorders and see the placement of a label as 'over-medicalizing' variations found in individuals.

Armstrong and Squires (2015) state that getting the label of dyslexia has notable personal implications for the individual (children and adults), can result in a causal chain of introspection and positively affect the individual emotionally by enhancing an understanding as well as provide reasons for the challenges experienced. However, the main purpose of labelling, apart from providing an understanding, is that it should lead to interventions which benefit the individual. If the label does not result in an improvement in the targeted and appropriate educational interventions, then the value of the label for the individual must be questioned (Lauchlan & Boyle, 2007). However, if the label provides eligibility for accommodations that can be made for such individuals, then its value is unquestionable (Ho, 2004). Kivi (2015)

makes reference to this advantage by stating that labelling can provide such learners with extra support and possibly allow them to receive instruction in smaller settings and at a pace suited to them, which could result in them overcoming or reducing their challenges.

Indirect advantages are referred to in Thomson (2012) where it is stated that labels provide a system of categorisation which enables research to be conducted into that category. It also provides the means for the challenge to be given a name which will allow for differentiation, and the label communicates the specific challenge in a meaningful and efficient way. Refusing to use diagnostic labels could result in the learners' challenges being minimised and research into the learning challenge is hampered as the result of not being able to find such learners because of a lack of diagnostic labels used (Bishop, 2014). Labels therefore provide a common language to describe the challenges faced. Bellair, Clark and Lynham (2014) reference the value of having a label, as found in the research, that can take place into it and secondly the intervention that could result and assist. Selikowitz (2012) also makes reference to the research that can be conducted by such persons and with such persons, thereby leading to an increase in the understanding of the learning challenges and possibly finding effective ways to assist. Labels can also be indirectly advantageous to such individuals if special interest groups are formed, to lobby for improved services, provide enlightening information and provide enlightened attitudes (Thomson, 2012). However, the positives of labelling in dyslexia cannot be experienced without society as a whole becoming more educated, as this could remove the negative judgements made and hence the stigma (Lawrence, 2009). The advantages of labelling are not solely confined to the individual, but include parents, teachers and society as whole.

If the diagnosis has been made correctly and by the relevant recognised persons to do so, the label is beneficial. Bishop (2014) reveals that the resultant positive consequences of living with a diagnostic label are:

- An explanation through the label is provided and it legitimises the challenge;
- Labels give a sense of belonging;
- An understanding and awareness of learning challenges is enhanced;
- Blame is removed from the individual, parents and teachers;
- Access is provided to extra funds, resources, and resource planning is enabled;
- Positive attributes of the individual can be focused on and emphasised;

- An awareness can be created possibly resulting in group action where the needs of the diagnosed person can be fought for;
- Targeted intervention can occur and progress of this person can be documented;
- Biological and social causes of the challenge can be recognised; and
- Research and generalisation across groups can be enabled.

2.4.4 Disadvantages of labelling

For various reasons, labelling is viewed by many as a negative concept, lacking advantages and should therefore never be used. It is seen as having its origins in the medical model of social disability and is therefore perceived as being oppressive (Solvang, 2007). Ho (2004) states that pathologising learning differences and providing a label that fits in with the medical model of learning disabilities is unnecessary and counterproductive, as it is far more important to design flexible curricula that can accommodate all learners and their learning styles. Arishi et al. (2017) view labels as indicating deviance, an indicator of abnormality which therefore violates the human rights of the person. Many researchers are against the use of labels as they view them as placing individuals in a box where their true worth and identity are hidden. Lawrence (2009) refers to this by stating the negativity of labelling is that sometimes the label is perceived first and then the individual, resulting in the label becoming part of the individual's self-concept and thereby dictating behaviour. The DSM-V emphasises that the importance for those with learning challenges is the specific personalised and individualised intervention that will be provided and not the specific label (American Psychiatric Association, 2013).

Disadvantages of labelling are viewed as starting with the diagnosis of dyslexia which can be controversial. It must be ensured that it is correctly done, that the correct label is given and that labelling must not simply be used on every learner/person who battles academically, fails or behaves badly (Arishi et al., 2017; Damico et al., 2013). The possibility that the classification/label given is incorrect, will always remain a possibility for those who are labelled (Lauchlan & Boyle, 2014) especially in the case of dyslexia where no single test is recognised. Claassens and Lessing (2015) state that diagnosing an individual with dyslexia, should never be used as a mechanism to label the individual but as a means of providing the necessary intervention. Whilst not specifically referring to the label of dyslexia, Lauchlan and Boyle (2014) are of the view that there is an over-reliance on labels and hence the use of labels.

Labels are viewed as "the handmaidens of societal biases and prejudices" that can result in stereotyping, wherein the individual is solely defined by the label and focus is placed on the characteristics of the label and intrinsic factors (originating in the person), whilst extrinsic factors such as teaching styles, are ignored (Damico et al., 2013, p.16). Cameron (2016, p. 235) states that the discourse around the dyslexia label is negative and says that the label is viewed by many as indicating a disability that places the individual as "an outsider within the educational system". Being treated as an outsider in the workplace because of having the dyslexia label is also indicated by adults. Learners thus become the labels that are given to them resulting in their individual personal characteristics being suppressed. Their new social identity takes over with the individual experiencing a difficult life as a result of the stigma and judgement placed on them by others (Boyle, 2014). Thomson (2012) concurs and states that labels can be harmful when they result in degradation, discrimination, exclusion in school or society and when individuality is lost. Lauchlan and Boyle (2014) see the negative experiences of labelling as ultimately leading to reduced opportunities in life. Therefore, as a result of the stigma and being discriminated against, the negatives of labelling far outweigh the positives (Algraigray & Boyle, 2017). Thomson (2012) however, indicates that it has to be acknowledged that individuals with challenges exist and no matter how much it is fought against, labels exist and pretending that they do not exist increases the stigma.

Labelling therefore tends to block out the realisation that the label refers to only one aspect of a person's life and that those with dyslexia are no different to those without it in terms of all people having both strengths and weaknesses (McLoughlin et al., 2002). Students in the study conducted by Osterholm et al. (2007) felt that the negative names that they were called prior to diagnosing, was the result of a presumed lack of understanding; however, it was also revealed that being diagnosed and labelled resulted in the same experiences that they had prior to diagnosis. Derogatory words such as stupid and retarded were still being used to describe them and teachers remained insensitive and sometimes publicly humiliated them. Labelling therefore leads to a catch-22 situation with whether to label or not, as stigma and negative attitudes are shown irrespective of whether a formal label is given or not.

Bornman and Rose (2017, p.24) are of the view that words have a strong influence on the way that people think and labelling "only serves to underline a child's shortcomings" and places the focus on the child's disability and not on the child's other characteristics. They indicate that the focus should be on providing the learner with the needed support and intervention to

facilitate learning by adapting the learning environment and not on the specific diagnosis. In looking to create this environment, can it truly be believed that the learner is not labelled when that learner is labelled as needing an adapted environment?

Whilst not generalising the results of the study, Conn (2016) found that labels create insecurity in education for the teachers, learners and parents and are actually viewed as disrupting the ecology of the school. They can either positively or negatively affect teacher classroom practice and act as a blindfold that prevents the teacher from actually getting to know the true worth of the learner (Arishi et al., 2017). Studies from the last five decades show that labels affect the teacher's expectations for that learner (Hammer, 2013). This is evident in some teachers who are judgemental and referred to as labellers because they promptly label any learner whom they view as being imperfect and having something that is wrong with them (The Secret Teacher, 2015). The Secret Teacher further states that these teachers make the learning challenge appear greater than it is, and use it as a tool used to discriminate against others by having lower expectations of and for them. Such actions impede the teacher's ability to look further than the label and explore the strengths and abilities of the individual. Osterholm et al. (2007) state that learning disability labels generate negative or lower expectations, negative stereotyping and attitudes leading to lower achievement as a result of reduced efforts. Lauchlan and Boyle (2014) state that this occurs when focus is placed on the within-child deficits leading to lowered expectation of what such a person can achieve. Jacobs (1978) explored the effect that the label has on teacher expectations on the school performance of labelled learners and was of the view that the label can have a negative impact on the teacher being able to objectively observe and interpret the learner's behaviour and therefore the label was viewed as causing bias. Forty years have passed since this finding and this review shows that few changes have occurred in teacher attitudes.

Bianco (2005) refers to the bias shown by both general and special education teachers who are influenced negatively by disability labels. This is seen in referral decisions made for learners to be included in gifted programmes as learners without labels are more readily referred to such programmes, which shows stereotyping (preventing teachers from seeing the true ability of these learners). Arishi et al. (2017) state that the only reason why labels and categories are sought by special education institutions is because of the resultant benefit of extra resources, but they question its value if they do not lead to the correct intervention programmes. They are of the firm view that "difference must be recognised as a beauty of life and we must change

the focus from labelling to a need because everyone at one point in their life has needs that must be met with additional support" (p.16).

Lauchlan and Boyle (2007) question the so-called benefits of labelling for parents. They are of the view that some individuals and families want a diagnosis in the perhaps erred belief that the label will lead to intervention and support, thus improving the life experiences and educational provisions for the individual. Bishop (2014) is of the view that there are disadvantages and negative consequences of labelling which includes:

- The label is viewed as indicating a problem that is solely placed within the individual, whilst the role of the environment is ignored;
- Focus is placed on what is wrong;
- The label could result in inevitable feelings of failure that lead to the individual no longer trying;
- Labels provide an excuse for bad teaching;
- The label is the focus and not the specific needs of the individual;
- Diagnostic criteria used for obtaining the label is unreliable;
- Non-medical disorders are medicalised; and
- The label results in changes made that are not beneficial to the individual.

The labelling of individuals will always be debatable, however the voice of those living with the label must be used to add or subtract to both the advantages and disadvantages of labelling.

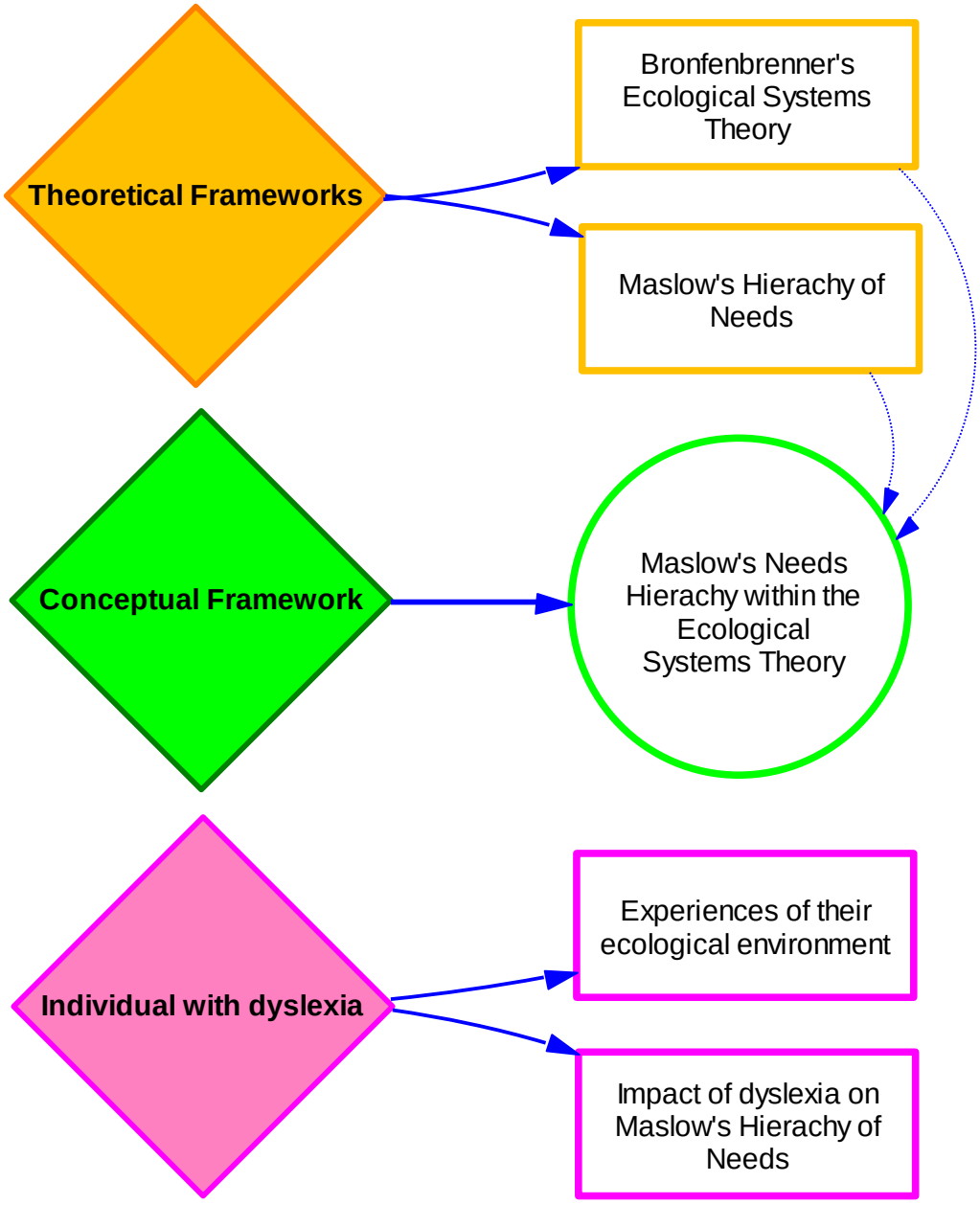
2.5 CONCLUSION

Literature discussed in this review was guided by the main research question. Background to the South African education system in which the participants in this study were educated, was provided. The various aspects of dyslexia commencing with the discovery of cases of dyslexia and concluding with the term and label in the present century was discussed. The literature review in this chapter concluded with labelling which is a component of the research question and hence this study. In Chapter 3, the frameworks selected for this study will be explained and reasons for their selection and suitability will be provided. Thereafter available literature on the individual with dyslexia will be explored. Their experiences, as well as the effects that dyslexia and labelling have on them will be discussed within the selected frameworks of the study.

CHAPTER 3

THEORETICAL FRAMEWORK AND THE INDIVIDUAL WITH DYSLEXIA

OVERVIEW OF THE CHAPTER



3.1 INTRODUCTION

Literature discussed in the previous chapter reflects that within the South African context there is little research focusing on dyslexia in educational institutions, workplaces and in society as a whole. Hence much of the literature discussed thus far was obtained from international sources. This chapter commences with the theoretical and conceptual frameworks selected to guide the study. Thereafter individuals with dyslexia are discussed within a review of literature that focuses on the experiences of these individuals. Continuing with the review of literature in this chapter is in keeping with the advice of Lichtman (2014), that a literature review in a study does not have to be confined to a specific literature review chapter.

The review of literature pertaining to individuals with dyslexia was guided by the frameworks selected as most suited to discovering and gaining insight into the lived experiences of adults who were diagnosed with dyslexia. The systems impacting on these experiences, as well as the possible effects on the needs of these individuals, are discussed. The selected frameworks used to obtain descriptions that detailed the various effects that dyslexia and labelling has on the life of such individuals, should produce answers to the research question asked by this study namely:

> **What are the described experiences of South African adults living with the label of dyslexia**?

3.2 THEORETICAL FRAMEWORKS

Theory is found in all qualitative studies and plays a vital role in achieving the aims of the study. Bearing this in mind, Schram (2006) emphasised that the theoretical and conceptual frameworks in a study must be selected with care as they enable the researcher to position the study within an established sphere of ideas. It is however, important to validate the selected frameworks' significance or relevance to the study.

A theoretical framework is an existing "blueprint" used to base and build the research inquiry, whilst the conceptual framework assists with the construction of the researcher's view of the value of investigating the phenomenon, thereby validating the worth of the study (Adom, Hussein & Adu-Agyem (2018, p.438). Bloomberg and Volpe (2016) state that whilst both frameworks place the study in an academic context and provide the lens used for viewing the study, the theoretical framework provides the scaffolding that guides all aspects of the study,

whilst the conceptual framework supports the study by providing the personal meaning or implications that the research answers have on the study participants.

Marshall and Rossman (2016) state that the theoretical framework should be based on a solid rationale that will show that the current study is based on something specific, that is linked to a large phenomenon or a larger theoretical construct and thereby reflect how the study serves to illuminate these larger issues. Maxwell (2013, p.40) positions the research question as part of the conceptual framework in that it identifies "something that is going on in the world" as well as justifies why the study is important. The conceptual framework therefore provides the researcher with a system or platform within which the research questions will be framed and it is used for categorising the data collected (Bloomberg & Volpe, 2016).

In selecting the frameworks for this study, the researcher was mindful of the aim of the study, which was to describe the experiences of those diagnosed with dyslexia and to gain a description of what it is to live with the label of dyslexia. People do not live in isolation; therefore, many external factors impact on intrinsic factors, and play a role in the dyslexic person's experiences of living with the label of dyslexia. This view is alluded to in Gibbs and Elliott (2015) where they state that whilst there is an obvious biological component in most instances of literacy challenges, the important relationship that individuals have with their environment is often overlooked. This environment is viewed by Solvang (2007) as the parents, educators, educational authorities and dyslexic organisations, who are the social actors that construct the social meaning of dyslexia. Conn (2016) provides an example of this within the school system. Here the label interacts with the entire school ecology comprised of the entire education system that learners finds themselves in, the pedagogical considerations experienced, the school structure, educators on a personal and teaching level, the curriculum and peers. Therefore each persons' lived experiences of their environments is unique because of their personal attributes and the way in which they interact with their environment (Leitão et al., 2017).

Taking cognisance of these views, the aim guiding the selection of the theoretical framework and conceptual framework for this study, was to encompass the world in which these persons live, and to place these individuals in the centre of their world. Bronfenbrenner's ecological systems theory (1979) is selected as relevant to guide the theoretical framework of this study and provide the systems that surround these individuals. This theory is used in conjunction with

Maslow's Hierarchy of Needs with both theoretical frameworks being combined to form the conceptual framework of the study. The conceptual framework is then used to describe and capture what life is like to live with the label of dyslexia and to discover if dyslexic individuals' needs are being fulfilled by the label. Implementing these frameworks allows a deep understanding of the influence and effects that the world has on labelled individuals.

3.2.1 Bronfenbrenner's Ecological Systems Theory

The Ecological Systems Theory (EST) was founded by Urie Bronfenbrenner (1917-2005), a world-famous theorist revered for his contribution to the field of developmental psychology. Today his theory is one of the most widely known and used theoretical frameworks in various disciplines and field of social sciences (Vélez-Agosto, Soto-Crespo, Vizcarrondo-Oppenheimer, Vega-Molina & García Coll, 2017). Present day world-wide use of this theory is found in major organisations including the World Health Organisation (WHO) and UNICEF who use it in their social programmes as well as in research (Vélez-Agosto et. al., 2017).

Bronfenbrenner based his theory on the premise that human life-span development does not occur in isolation, but within multiple environments ranging from immediate to extended, therefore, an understanding of human development can only occur if the entire ecological system in which growth occurs is looked at (Bronfenbrenner, 1994). He referred to the environments that surround individuals as ecological systems. He initially called his theory an ecological systems theory, which comprised of three layers or systems with the child in the centre, surrounded by the upper layer or immediate settings such as the home, school, and so on, and the third outer or supportive layer that determined what happened in the inner layers (Bronfenbrenner, 1994). In 1977, he extended the theory to include five systems and renamed it the 'bioecological systems theory' to emphasise the role played by the child's intrinsic biology as the primary environment that shapes development (Paquette & Ryan, 2011). However, the first name given to this theory is still widely used today.

The interaction between the factors in a environment such as the family, school and communities guides and steers a person's development and that interaction in turn between these subsystems, can affect each other (Bronfenbrenner, 1994). This theory is therefore a scientific approach that places emphasis on the interrelationship of the various systems surrounding the child and an approach that notes contextual variation (Darling, 2007). This contextual variation contributes differently to the effects and influences on both the

development and behaviour of the child (Schram, 2006). It stresses that development is affected by the quality and context of the systems surrounding the child (Harkonen, 2007). Bronfenbrenner named two environmental conditions essential for positive human development and growth, namely that adults closest to the child must show unconditional love, and that they must encourage the child as well as spend quality time with the child both in and out of the home (Boemmel & Briscoe, 2001). He was of the firm view that insight and understanding into the direct and indirect influences in a child's life and development could only be gained by looking at the different levels of the environment that surround the child, and noting the impact that it has on each of these.

The characteristics and development of the child and the reactions of others within their social context are viewed as interactional (Paquette & Ryan, 2001). The various systems influence and affect each other in a bidirectional manner, forming a network of effects that are interdependent, therefore children are both products, as well as producers, of their environment (Berk, 2009). To gain an understanding of human development, systematic information about the context that surrounds the child and the processes through which development occurs has to be noted, as failure to do so produces a flawed understanding of such development, because of it being out of context (Jaeger, 2012). The influences of the various systems include economic and political structures that are part of the life course of children throughout their lives, and are important components in shaping development. Realisation of the influence that the various systems have on children's development, has led to Bronfenbrenner's theory influencing the way in which psychologists approach the study of human development and their environments (Rajput, 2012).

Bronfenbrenner depicted his ecological environment as a "set of nested structures, each inside the next, like a set of Russian dolls" (Bronfenbrenner, 1979, p.1). The model is often depicted as concentric circles, where each circle has a bidirectional influence on the circles inside it and a bidirectional influence on the structures within each circle (Bronfenbrenner, 1994). Boemmel and Briscoe (2001) referred to the influence as a ripple effect that takes places within the systems. Bronfenbrenner initially identified four structures or systems in which maturation and development occurs, starting from the child in the centre, namely the microsystem, mesosystem, exosystem and macrosystem and later added a fifth system namely the chronosystem which is based on time (Harkonen, 2007). Darling (2007, p.203) aptly refers to EST as one that "places the person in the centre of the circles". With the person in the centre,

the continuous interaction between the factors in an environment such as the family, school and communities guides and steers a person's development, and interaction in turn between these subsystems can affect or influence each other (Bronfenbrenner, 1994). Figure 3.1 depicts four of the five systems forming the EST and shows the role players found in these systems. This figure has been adapted to depict the macrosystem that is relevant to SA individuals.

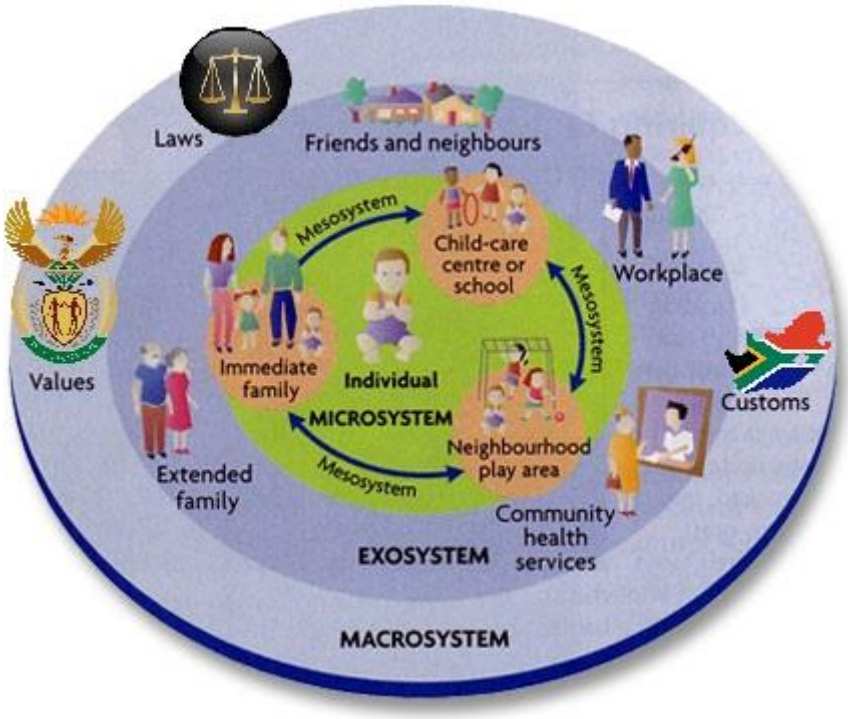


Figure 3.1: Bronfenbrenner's Ecological Systems Theory (adapted from Berk & Roberts, 2009, p.28)

3.2.1.1 Microsystem

The microsystem depicted in Figure 3.1 is referred to as the inner level and is therefore "the immediate setting containing the developing person" and is comprised of the child and the relationships with those who are closest, for example parents, siblings and possibly caregivers (Bronfenbrenner, 1979, p.1). Persons in this system have their child's distinctive physical, social and symbolic characteristics (Bronfenbrenner, 1994), which includes temperament, personality and their own system of beliefs (Harkonen, 2007). Bronfenbrenner was of the view that because continuous close face-to-face contact with persons in this system occurs, the child is constantly shaped by interactions herein, including the way in which the child perceives these interactions. Such interactions are perceived to be responsible for shaping the psychological growth of the developing child (Bronfenbrenner, 1979). Watling, Neal and Neal (2013) provide

examples of such interactions which include family meals eaten together, mum reading to their child and playing with siblings.

Interactions must be viewed as bidirectional where it is not only adults who affect the developing child, but also biological characteristics such as personalities of the developing child that can affect the behaviour of adults towards them (Berk, 2009). Berk provides an example validating this where she states that a child who is friendly and easy to handle evokes positive responses from adults, whereas a difficult child evokes negative responses such as scolding and punishment. Paquette and Ryan (2001) provide an example of the bidirectional interactions wherein they state that the beliefs and feelings of parents and children affect each other positively or negatively, and it is a relationship where encouragement or discouragement is shown and experienced. In this study, focus in the microsystem is directed at individuals who are the persons diagnosed with dyslexia and hence living with the label. Particular focus is placed on their life relationships and experiences with their parents, caregivers, siblings, peers, teachers, principals, educational institutions and workplaces, based on them having dyslexia. Support from those in the microsystem should encourage positive interactions and experiences.

3.2.1.2 Mesosystem

The next level in Figure 3.1 is the mesosystem, comprised of the relations, links or interconnections between the elements in the inner level (Bronfenbrenner, 1979). The mesosystem surrounds the microsystem and does not describe people, but focuses on the communication and relationship that occurs between those within the microsystem; for example, meetings between educators and parents (Bronfenbrenner, 1994). The mesosystem therefore consists of the organisational or institutional factors that are responsible for the structure of the environment in which the child and the interpersonal relationships in the microsystem occur (Rajput, 2012).

Bronfenbrenner refers to the mesosystem as being a system of microsystems that is formed when the child moves into a new setting and where the child actively participates (Bronfenbrenner, 1979). He provides an example wherein he states that a child's ability in reading is not only dependant on teaching, but also on the relationship and involvement that exists between the home and the school. A positive link between the home, school and neighbourhood results in positive support and hence positive development for the child.

However, Berk (2009) states that less affluent homes are more dependent on this positive relationship than those from affluent homes, resulting from the latter being able to provide for the child. This alludes to the contextual variation referred to by Bronfenbrenner. Relevant to this study in this system are the relationships, links and influences between the parents, siblings, caregivers, peers, school, social life and the workplace.

3.2.1.3 Exosystem

Figure 3.1 places the exosystem in the third level which surrounds the mesosystem. It comprises of one or more social settings that do not involve the child as an active participant; however, the child is affected by the events that occur, or what happens in this system (Bronfenbrenner, 1979). The exosystem refers to the links that exist such as parents' place of work, extended family, the neighbourhood, religious institutions and health and welfare services. Bronfenbrenner states that even though the exosystem is a level that does not affect the child directly, it has an indirect positive or negative effect on the child. Berk (2009) provides examples such as the parents being allowed to take time off work to keep appointments made to assist with the child's needs, friends and extended family providing advice or even financial assistance. A breakdown in this system has a negative impact on the child. The exosystem acknowledges that the person's development is "affected by events occurring in settings in which the person is not even present" (Bronfenbrenner, 1979, p.1); for example, parents' working conditions, the parents' friends, or the school governing board or school system. In this study, the exosystem includes the influences and experiences of school policies, mass media, local government policies and workplace policies.

3.2.1.4 Macrosystem

The macrosystem depicted in Figure 3.1 is the level that is furthest away from the child and signifies cultural and societal beliefs, values and ideologies in which the above-mentioned systems are embedded, and are therefore relevant to the society in which the child develops (Bronfenbrenner, 1979). Harkonen (2007) refers to this system as the blueprint of a society's culture or subculture. Bronfenbrenner (1994) states that it includes all that is embedded in the belief systems, resources, lifestyles, customs, provision of opportunities or options of the society. He states that the system in which a child the finds him/herself could differ from those of others, resulting from the various "socioeconomic, ethnic, religious and other subcultural groups" which could propagate different belief systems, customs and lifestyles (p.26). This attests to the contextual variation noted by Bronfenbrenner.

Berk (2009) states that the priority given by the macrosystem to the needs of the child, impacts and affects the support received from the inner levels of the system. This system has therefore had a cascading or ripple effect on the inner systems. An example of this effect is seen in Spain where the word dyslexia is not used, as it is believed that if a person has it, nothing can be done to assist or help the child, whereas if their need is SEN they are protected by the Organic Law of Education, which stipulates that schools have to provide tutors for such learners (González Seijas, 2011). Legislated policy can therefore place limitations on the support received by these individuals, thus causing a ripple effect on all surrounding systems. In the context of this study, which is located in SA, this system refers to the level at which policy decisions in education are made, namely the Department of Education which provides guidelines on the implementation of various policies drawn up by the Department. Workplace policies are guided by the South African Employment Equity Act and the Department of Labour.

3.2.1.5 Chronosystem

The chronosystem is the outer system that encompasses all the systems surrounding individuals. Bronfenbrenner viewed the environment surrounding children as ever changing thereby affecting individuals who are also changing as a result of maturation (Bronfenbrenner, 1994). The chronosystem is the level that embodies the changes that occur in any of the systems over time (Bornman & Rose, 2017) and therefore represents the ever-changing nature of individuals and their experiences (Berk, 2009). Changes can be imposed on the child or they can arise directly from the child as a result of getting older. Maturation results in individuals having the ability to choose, change or create their own setting and experiences, of which all are dependent on the child's physical, intellectual and personality characteristics as well as their environmental opportunities (Berk, 2009). Such changes can include change in the structure of the family, change in address, changes in parents' employment, changes as a result of the child maturing and going into the workplace, as well as societal changes. The chronosystem therefore notes the impact that time has on individuals and their surrounding systems (Jaeger, 2012).

Using Bronfenbrenner's Ecological Systems Theory, and recognising that individuals lived experience are unique, the interactional relationships and influences that the different systems have on individuals as a result of being diagnosed and hence living with the label of dyslexia, are described. This description includes their development and aging experiences in the context in which they were found. However, this study is cognisant that these experiences are possibly

influenced by the lens of the medical and social models of disability, as well as positive psychology, as discussed in 1.4.7, of those in the various ecological systems of individuals with dyslexia. Possible views and actions of those in the surrounding systems of these individuals are depicted in Figure 3.2.

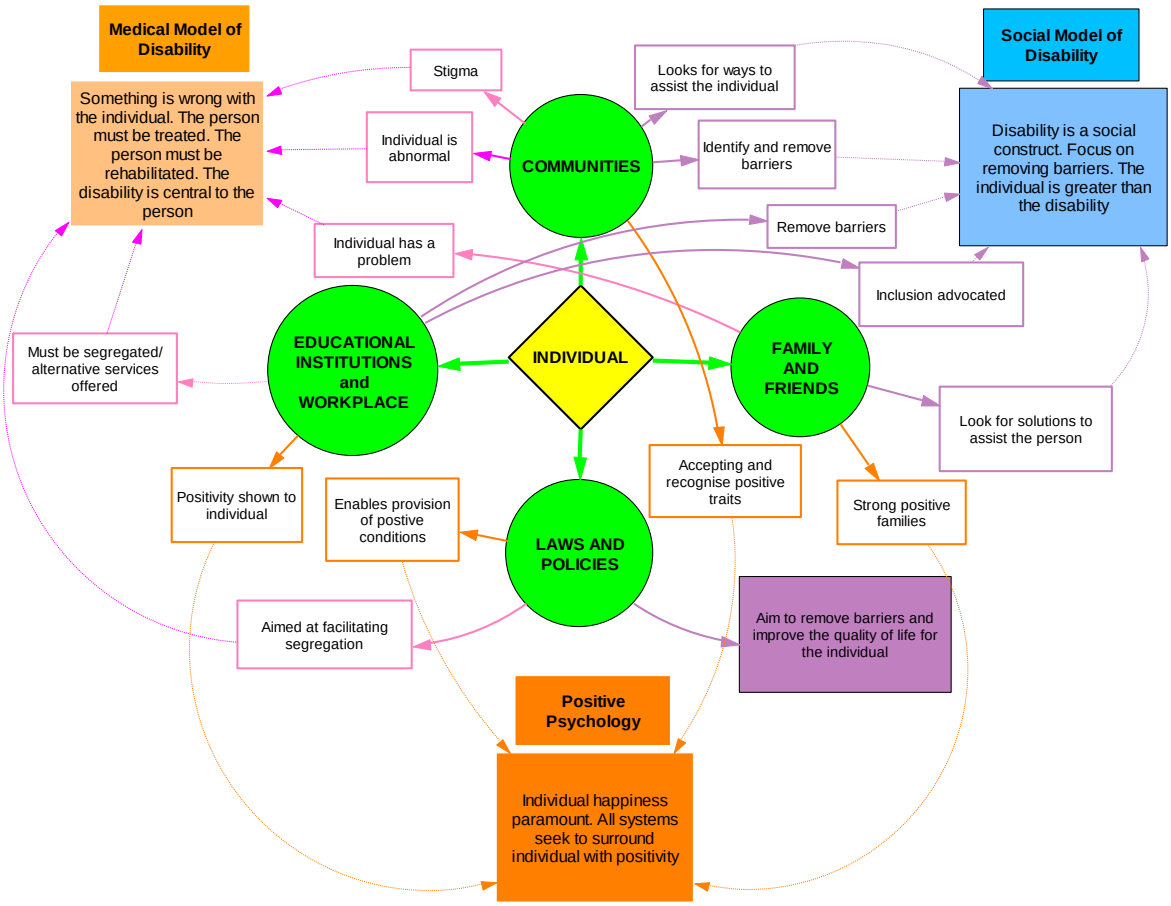


Figure 3.2: Lens used by the medical, social and positive psychology models for those with dyslexia

Algraigray and Boyle (2017) believe that phrases and words are decisive in shaping people's perceptions of individuals who are labelled. Such perceptions, attitudes and actions are controlled by the lens used. Therefore, in keeping with Ho (2004), who suggests that the social, cultural, economic, formal learning environment and family environmental conditions must be looked at to understand the complex context of the learner's academic performance and lived experiences, my selection of EST as one of two frameworks in this study was reinforced.

3.2.2 Maslow's Hierarchy of Needs

Abraham H. Maslow (1908-1970) was an influential psychologist who contributed greatly to psychology in the 20th century with his theory of human motivation, referred to as a hierarchy of needs. He believed that motivational life is that which is built on goals or needs where motivation is a "pull' more than a "push" (Maslow, 1970, p.26). He therefore postulated that human needs are organised into a hierarchy of dominance (Maslow, 1987) or a pecking order of importance. He viewed this hierarchy of needs as common to all human beings and that people are motivated to achieve needs, starting from the base of the pyramid. Maslow named the five levels in the hierarchy of needs namely, physiological needs, safety needs, belongingness and love needs, esteem needs and self-actualisation. Maslow (1970) acknowledged that unlike the needs in the lower levels of the hierarchy, those in the upper levels are not essential for survival; therefore, the achievement of these needs can be delayed. Maslow's hierarchy of needs is depicted as a five stage/tiered pyramid as shown in Figure 3.3 where the bottom two tiers represent basic needs, the third and fourth tiers psychological needs and the top tier refers to the achieving self-fulfilment.

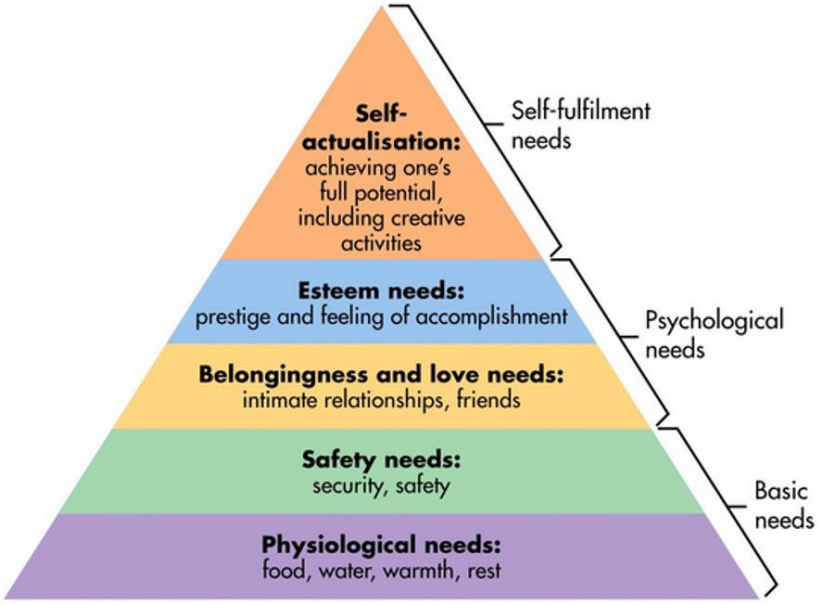


Figure 3.3: Maslow's Hierarchy of Needs (McLeod, 2018)

Initially Maslow stated that as the needs in each tier are met, individuals are motivated to move up the hierarchy to fulfil the needs on the next tier, until the top level is reached and achieved (Maslow, 1943). He believed that achieving the needs in a tier, resulted in satisfied individuals, with those needs no longer being important to them (Guo, 2015). Maslow however, changed his view in later years and stated that the order of the hierarchy "is not nearly as rigid" as he had earlier implied (Maslow, 1987, p.68) and that the needs in each tier do not have to be

completely achieved before progressing to the next tier. Maslow (1970) acknowledged that most normal individuals are both partially satisfied and unsatisfied in all their basic needs.

Movement between the tiers is therefore not confined to an upward direction only. Disruptions to this upward movement can be caused by the death of loved ones, divorce and loss of employment, thus resulting in individuals moving down the hierarchy to once again attempting to satisfy lower needs (McLeod, 2018). Disruptions however, are not only caused by negative events but also by positive occurrences such as marriage, becoming a parent or a change in career (Caraccio, 2017). Therefore, a yo-yo effect is often experienced between the tiers. Re-evaluating of needs depends on what individuals judge as being important and this results in the readjustment of the levels and needs on the hierarchy pyramid (Maslow, 1943). Barriers to the achievement of these needs for those with a learning challenge include personal barriers that are intrinsic (skills, family literacy levels and family finances), environmental barriers that are imposed by society or the environment, policy barriers that limit support systems, attitudinal barriers caused by opinions and beliefs and knowledge and skills barriers found in educators (Bornman & Rose, 2017).

3.2.2.1 Basic Needs

Maslow placed the first two tiers starting from the base of the pyramid into the category of basic needs. This category is comprised of physiological needs and safety needs.

- **Physiological needs**

Maslow (1954) referred to these needs are the starting point of motivation and therefore placed them at the base of the pyramid (first tier). They are referred to as basic needs that are necessary for survival and therefore human existence, and includes food, air, water, shelter and warmth amongst other basic needs (Maslow, 1954). Physiological needs are viewed as being the most dominant of all the needs and as a major motivation for all humans above any of the other needs (Maslow, 1987). Therefore, if physiological needs are not met all needs in the upper tiers become irrelevant. He provides the example of a hungry person's focus being solely on satisfying their hunger thus resulting in all other unfulfilled needs in higher tiers becoming insignificant or non-existent. Thoughts of food totally consume individuals, whose main aim is to end hunger, thereby leading them to believe that satisfying this basic need of hunger will make them the happiest person in the world. Maslow was of the view that once basic needs are

met, even if just to a certain degree, higher needs or needs in the next tier are focused on with the aim of achieving these needs. A new set of higher-level needs therefore emerges.

- **Safety needs**

These needs are in the second tier of the pyramid and encompass "security, stability, dependency, protection, freedom from fear, from anxiety and chaos, need for structure, order, law, limits…." Maslow (1954, p.39). It is usually the duty or role of parents to ensure that the safety needs of young children are met; however, here too Maslow notes contextual variation and states that for many fortunate adults these basic needs are usually satisfied and they are also often ensured by the society in which the person lives. Unstable environments caused for example by crime, terrorism or war, negatively impacts the safety needs of individuals residing here. Maslow (1943) attributed maladjustment and psychopathology in individuals as being caused by their safety needs not being met. With changes to the modern world, Maslow (1987) included medical, dental, employment, disability and security, in the aging years of lives, as part of modern-day safety needs.

3.2.2.2 Psychological needs

The second category of needs are psychological needs and are comprised of belonging and love needs as well as esteem needs, which comprise the third and fourth tiers in the hierarchy.

- **Belongingness and love needs**

The third tier of the hierarchy comprises the belonging and love needs. Maslow (1987) viewed these needs as emerging and becoming a goal for individuals, once certain degrees of the physiological and safety needs are met. The reason for this is that needs that are met, are no longer important or significant thus resulting in ignoring the needs achieved and moving up on the hierarchy (Guo, 2015).

Belonging and love needs arise as individuals mature from babyhood and develop relationships both in and out of the home. These needs include friendships, trust and acceptance, love, affection and aligning to others that are within their circle (McLeod, 2018) and are needs that most aspire to experience. Maslow views love needs as reciprocal where it involves both giving and receiving, and states that whilst there is no scientific evidence for belonging, the value of belonging in terms of family, friends and neighbours exists and is also revealed in the animal kingdom. In this study, parents, siblings, educators, peers, partners, spouses are focussed on in

relation to fulfilling the dyslexic individuals' belonging and love needs with the emphasis on love or affection as well as acceptance.

- **Esteem needs**

Maslow (1987) classified these needs into two categories with the first referring to individuals' need to achieve, be strong, confident, adequate, experience mastery and competence and to have freedom and independence. The second category refers to the reputation and prestige of individuals where they desire to be respected, appreciated and recognised by others, as well as to be seen as persons with dignity. Maslow (1954, p.45) states that the satisfaction of these needs in these two categories enhances self-esteem, which in turn positively affects "feelings of self-confidence, worth, strength, capability and adequacy, being useful and necessary to the world" whilst the opposite has negative effects resulting in feelings of inferiority and helplessness. Literature, discussed in this chapter reveals that the needs in the two categories in this tier are greatly affected by individuals diagnosed with dyslexia and living with the label, with the effect being determined by the influence of the various role players in the individuals system. Once the needs in the lower four tiers are met, motivation increases resulting in the highest level becoming the goal (McLeod, 2018).

3.2.2.3 Self-actualisation

The last or ultimate tier is self-actualisation and is found at the point of the pyramid. Maslow based his theory on the belief that human actions are all directed to goal attainment and that as lower level needs are met, individuals becomes discontented and restless until they achieve what they feel was meant to be achieved (Maslow, 1987). Self-actualisation is seen as the ultimate goal and can be equated with what individuals are born to achieve, and achievement herein is viewed as reaching one's maximum potential (Guo, 2015). It can therefore be equated with self-fulfilment. In Maslow (1970), the achievement of self-actualisation is stated as only occurring in older persons based on the premise that those who are younger do not achieve based on them being unsure of themselves which is the result of not achieving an identity, experiencing fulfilling love relationships as adults and not having their own set of values. Therefore, as a result of the lower tiers being fulfilled when younger and not as adults, many individuals return to the lower tiers again, before self-actualisation is achieved. Maslow however, was of the belief that the achievement of higher-level needs is not essential for survival. However, attainment of these needs can result in adults experiencing greater longevity, being healthier, and therefore showing positive physical and psychological

characteristics. Therefore, achieving higher level needs could result in individuals who are happy, calm and enjoy a richer and fuller life.

Maslow (1987) however, states that specific needs at this level differ for individuals, and are personalised; however, common characteristics are shared. He therefore places focus on the personality of individuals. Maslow's conceptualisation of self-actualised individuals is that they are relaxed, they have satisfied their needs for safety, belonging, love, respect and self-esteem, they are individuals who are engaged in fulfilling their needs for knowledge and understanding, and as having developed their "philosophical, religious and axiological bearings" (Wertz et al., 2011, p.31). Maslow stated that 'self-actualisation' should not just be conceived statistically, as a rare achievement, as an all- or non- achievement, but as something in a person's life that takes place on a continuum where the self-actualised person has peak experiences frequently (Wertz et al). Maslow refers to those who achieve self-actualisation as being satisfied persons as their needs on the lower levels of the hierarchy have been met but acknowledges that those who achieve this are the exceptions in society.

3.3 CONCEPTUAL FRAMEWORK

Maslow's hierarchy of needs within Bronfenbrenner's ecological systems theory are combined to form the conceptual framework for this study, as depicted in Figure 3.4. Both theoretical frameworks and hence the conceptual framework are used to discuss literature pertaining to the third concept of the study, namely individuals who are diagnosed with dyslexia. Placing these individuals in the centre and encompassed by systems, as proposed by Bronfenbrenner, the review of literature focuses on individuals living with this learning challenge. Included are the possible effects that dyslexia and the label of dyslexia have on the experiences and needs of these individuals as well as the influences of the various systems involved in these experiences. As previously stated, very little research in SA has taken place herein therefore literature, unless indicated as SA, is from other countries.

Conceptual frameworks in a study are valuable as they assist in reducing theoretical data into statements or themes, providing a theoretical bases to design research, as well as providing the framework for the interpretation of the findings and conclusions (Leshem & Trafford, 2007) The value of the selected conceptual framework lies in it being used as an analytical tool and hence a lens for the framing and viewing of the findings of this study. Hopefully this framework

together with the use of phenomenology, will reveal if progression within Maslow's tiers can be achieved by those living with dyslexia and thus with the label of dyslexia, as well as render results that could indicate the worth of the label.

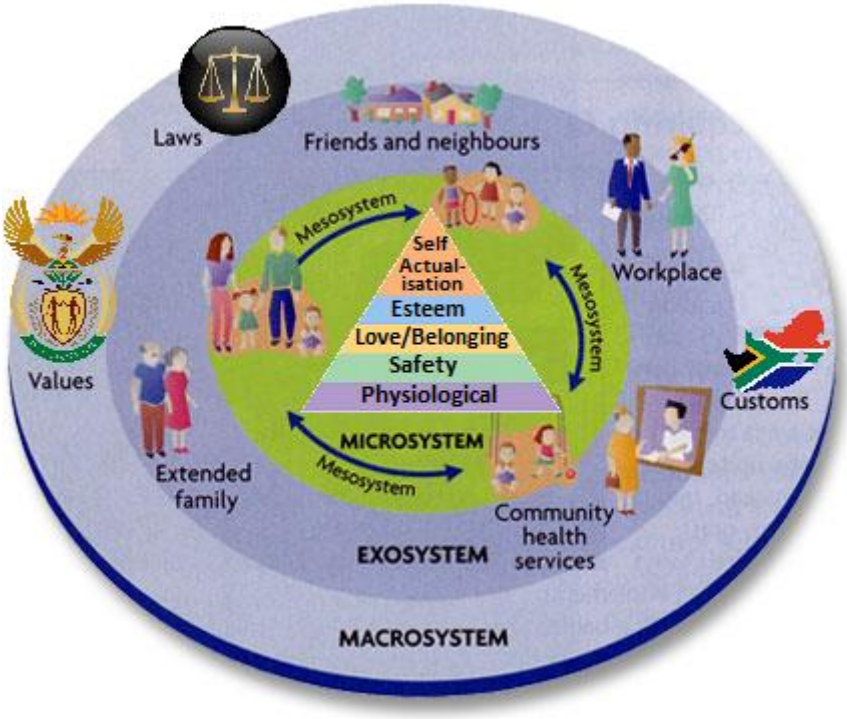


Figure 3.4: The Conceptual Framework (illustration adapted from Berk & Roberts, 2009, p.28; McLeod, 2018)

3.4 INDIVIDUALS DIAGNOSED WITH DYSLEXIA

Individuals diagnosed with dyslexia are identified as being one of three concepts underpinning this study. All three concepts, namely dyslexia, labelling and diagnosed individuals overlap, as depicted in the Venn diagram in Figure 3.5, showing the influence and effect that they have each other. The "X" in this diagram reflects that this study is found in the centre of the overlaps.

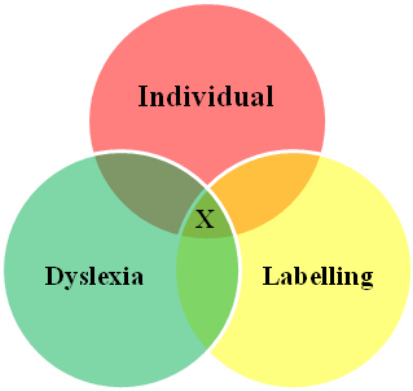


Figure 3.5: Concepts of the study

As a literature review on dyslexia and labelling has been conducted in Chapter 2, literature pertaining to individuals diagnosed with dyslexia is discussed below. Literature in the previous chapter indicates that living with dyslexia can be challenging. Challenges are aggravated by a lack of understanding, acknowledgment of the existence of dyslexia, diagnoses and support, as well as not receiving appropriate intervention in education and in the workplace. This causes those with dyslexia to often feel frustrated, they struggle to cope with work, feel exhausted from trying and many lack confidence (Goodwin & Thomson, 2012). However, it is important to note that these experiences are mainly conveyed through the voices of parents and educators and rarely from accounts given by those with dyslexia (Ingesson, 2007), thus validating the importance of this study. This section of the review, in keeping with the aims of the study, will focus on what is known about the experiences and feelings of adults and learners with dyslexia, as told by them. The role, influences and impact of the ecological systems on their experiences, as well as the effects of these on the needs identified by Maslow are described.

3.4.1 Individual's experiences of dyslexia within their ecological system

Studies confirm that dyslexia is a lifelong learning challenge that follows individuals through primary, secondary and tertiary education into adulthood, into relationships formed as well as into the workplace. Dyslexia's ever presence in life is attested to by many adults with dyslexia, as will be discussed. Recollections of life experiences focusing on their dyslexia challenges revolves around the systems that surround them namely, their family, school, educators, peers, society, as well as policy and laws.

3.4.1.1 Diagnosis and Acceptance

- **Adults**

Studies reveal that many with dyslexia are only diagnosed as adults or when students are in tertiary education (Bell, 2010), thus indicating the failure of their surrounding systems in assisting them to understand their challenges. Literature discussed hereunder, reveals that many adults are not formally diagnosed and that various circumstances or events have led them to realise that the challenges and frustrations personally endured were as a result of having dyslexia. Feelings of despair are expressed, feelings that many negative experiences could have been avoided if their dyslexia was known and diagnosed, thus alluding to the failure of their ecosystem in providing assistance and understanding.

Literature reveals that many dyslexics only discover when they are adults that their learning challenge has a name. A parent's realisation of being dyslexic after having a child diagnosed with this learning challenge is mentioned in Grimes (2009). Henry Winkler, a famous actor, discovered he had dyslexia at the age of 31, as a result of his stepson being diagnosed (Zipzer, 2007). Despite his accomplished fame, this realisation led to feelings of anger, resulting from knowing that there could have been more understanding from all role players in his system if his dyslexia was known. The realisation of having dyslexia after listening to a talk about this learning challenge is referred to in McLoughlin et al. (2002). This realisation provided relief and closure, in that it furnished answers for the challenges encountered and the realisation of not being bad, stupid, thick, lazy or worthless. These were the negative connotations that had plagued her, throughout her life. Individuals who are diagnosed as adults reveal that diagnosis was life-changing as it provided relief and assisted in them no longer doubting their intelligence (Hanning, 2016). Gerken (2016) aptly sums up the effects of being diagnosed with dyslexia by stating that it embraces many meanings and emotions that are empowering, liberating and it provides the best feeling in the world of knowing that you are not stupid, slow or have a low IQ. Therefore, diagnosis can aid understanding and provide these adults with tools to transform their identities from the negativity of having a low intelligence into positivity based on being different but able (Macdonald, 2009).

However, tertiary students' reactions reveal that being told that they have dyslexia is not enough of an explanation of the label, particularly if assistance is not provided, as without this they still have feelings of being thick, dumb and stupid, which negatively affects self-confidence (McLoughlin et al., 2002). Therefore, whilst a diagnosis at an earlier age is revealed as possibly negating many educational experiences that cause much pain and anguish, providing the appropriate intervention within the ecosystem of these individuals, is essential for all, irrespective of age (Rose, 2009).

- **Young learners**

Reactions to a diagnosis of dyslexia as well as the acceptance of having this challenge vary, and are often influenced and thus affected by the ecological systems that surround them. Literature reveals reactions as being positive, negative or an attitude of disregard or denial is shown, where their dyslexia is viewed as a non-existent challenge thus resulting in detachment. Positivity is exhibited when contentment with the diagnosis occurs with individuals stating that they would never wish for it to go away and therefore be non-dyslexic (Leloup & Sprenger-

Charolles, 2011). Such individuals embrace their dyslexia as a strength and view it as the key to their success as it makes them work harder to succeed (Rosetti & Henderson, 2013). Some reveal that their diagnosis was reaffirming because it provided an explanation for the challenges experienced (Leitão et al., 2017). Knowing that others with dyslexia have been able to achieve, has increased their feelings of pride and self-worth, thus decreasing the embarrassment of diagnosis (Shahin, 2011).

However, a positive reaction to a diagnosis is not unanimous, as revealed in Ingesson (2011) where individuals expressed their wish that their dyslexia would leave them. Such negative reactions result from dyslexia being viewed as making them different to their peers, and as a lifelong burden (Leitão et al., 2017). The ramification of such negativity can lead to the suppression of all feelings and thoughts associated with dyslexia (Gur & Share, 2011) and avoidance or refusing to accept and acknowledge the challenge. This concurs with Gyarmathy (2011) and Hoskins (2015) who encountered learners with dyslexia displaying denial of their challenges. They indicated that reading and books are a passion for them, even though it was revealed by third parties that these learners avoided reading because of the challenges experienced.

The role of various systems in acceptance of the diagnosis and hence living with the challenge, is referred to in Rose (2009) who states that positive reactions to a diagnosis is dependent on an explanation being provided so as to enhance an understanding of what dyslexia is and means. Rose indicates that such an explanation will enable these individuals to gain an understanding of what is 'wrong' with them, why the challenges are experienced and that the challenges have a name. Ingesson (2007) concurs and states that an explanation from those in the surrounding systems assists acceptance, as not knowing the meaning of the diagnosis often evokes feelings of pain and embarrassment, whilst acceptance provides relief in knowing that the challenges are not the result of being stupid. Stringer et al. (2011) indicated that an explanation and the provision of appropriate interventions to those with dyslexia are the keys to acceptance and achievement. This was validated by individuals who stated that such an intervention led to an improvement in their reading, self-confidence, and hence contributed to their success (Stringer et al., 2011), thereby positively impacting on the attainment of Maslow's identified needs.

3.4.1.2 Education

Various attitudes and emotions to education are expressed, and the influence and role of the surrounding ecological systems of individuals are often referred to. Parents, schools, educators and peers are indicated as having a crucial role in contributing to the quality of their lived educational experiences, with many indicating that despite being surrounded by others, they internalise their feelings and emotions more frequently than externalising them (Leitão et al., 2017). Schooling experiences of both adults and young learners are commonly described as being negative.

Adults indicate that the school environment was inflexible and that they were continually compared to their peers thus causing them to view and feel that their dyslexia was a burden and hence a disability (Alexander-Passe, 2015a). These experiences and views appeared to be compounded by their failure to understand why they were different, and why they experienced literacy challenges, despite trying their best. Winkler, despite his adult success and wealth, indicated that school was a nightmare for him, equated it to climbing Mount Everest naked, and attributed his negative feelings as being caused by educators who did not have any time or patience for him (Zipzer, 2007). Young children concur with these experiences. They describe schools as an inflexible environment that offered no escape from reading and writing, and having to endure constant comparisons made with the abilities of their peers, thus resulting in them not liking school (Chu et al., 2011). Many describe their feelings of anger, frustration, being unable to help themselves and unhappiness, which is often compounded by the school not providing for their needs (Wearmouth, 2004). These feelings were aggravated through the realisation that something was not right, not understanding why the challenges were experienced and feelings of being "the most stupid child in the class" (Ingesson, 2007, p.578).

However, such negative feelings are shown to reduce with maturity and when reaching the level of high school, some learners with dyslexia expressed feeling more relaxed and comfortable (Alexander-Passe, 2015a; Ingesson, 2007). Negating these feelings are experienced by those with strong support systems which lead learners to develop positive attitudes towards school, have strong academic ambitions, a hunger for knowledge and knowing the value of hard work (Gyarmathy, 2011). This attests to the significance of schools providing appropriate interventions for such learners to enhance success for those with dyslexia, as emphasised in Rose (2009). The role of schools and appropriate interventions are crucial factors in reducing the negative feelings resulting from having dyslexia.

The macrosystem surrounding these individuals and the education policies arising from this system play an important role in the provision of appropriate interventions for these learners. Studies reveal that the type of school attended affects school experiences. Learners with dyslexia in special schools in Ireland reported positive school experiences where they enjoyed school and having friends, whereas this experience was not shared by learners with dyslexia in mainstream schools, where many encountered unfriendly peers (Nugent, 2008). This finding is aligned with Leseyane, Mandende, Makgaro and Cekiso's (2018) study where learners with dyslexia in mainstream schools indicated negative school experiences as a result of impatient educators who embarrassed them and used negative comments on them.

Educators therefore play a pivotal role in the school experiences of learners with dyslexia, thereby impacting on the attainment of their needs. Many describe their early years at school as being a place of torture, as being in a prison, as constantly struggling, being embarrassed by their educators and continually being misunderstood by them (Rosetti & Henderson, 2013). Being humiliated by educators is revealed as a frequent occurrence in Gyarmathy (2011), Ingesson (2011) and Skaloumbakas (2011) where learners hated school and wanted to rather stay at home because of constantly being reminded of their challenges, being insulted and called an idiot. Included in these experiences was extreme physical behaviour shown by an educator who bullied and slapped a learner in the face for not complying and making fun of this educator. The role of educators is also referred to in Heimdahl Mattson and Roll-Pettersson (2007) where the majority of educators were stated as being unhelpful, refusing to alter their methods or showing an understanding that school work could be done differently. Educators are seen as avoiding the challenges faced by those with dyslexia; however, a few educators were acknowledged as showing an interest and positive attitude to these learners, thereby showing their belief that those with dyslexia can succeed (Heimdahl Mattson & Roll-Pettersson). In order to cope, some learners wished that educators would assist them, slow down their teaching pace, spend more time with them, explain work not understood during lunch breaks and not to be shunned and told that they are bad or stupid (Anderson & Meier-Hedde; 2011; Capellini, et al., 2011; Meier-Hedde, 2011). As a result of these experiences, some with dyslexia blame their educators for causing their failure and not their reading challenges, as the educators' actions are seen as lacking in understanding and also not providing assistance that is needed (Meier-Hedde, 2011).

However, blame is also apportioned to parents for contributing to their negative experiences wherein a lack of understanding was occasionally encountered from both educators and parents, who refer to them as useless, at the bottom of the group, in need of special help for reading, being asked why they can't read when everyone else can, and being told that they can read if they tried (Armstrong & Squires, 2015). Reading aloud is revealed as being a deeply humiliating experience that makes them self-conscious, highlights their inadequacies, and this was compounded if peers ridiculed them or laughed at them whilst listening to them reading aloud (Casserly, 2011; Rose, 2009). Such negativity often results in the avoidance of reading or reducing the effort and persistence made herein, resulting in an increase in the gap between themselves and their peers (Armstrong & Squires).

The role and power of words and actions from those in various systems can strip these individuals of their self-confidence thereby affecting the attainment of their basic needs. It can result in a mindset of being inept, as despite the effort put into their schoolwork, the feedback can be negative, they experience being rebuked, being called lazy and having to do the work again (Wearmouth, 2004). Such negativity causes these learners to view themselves as incompetent, lazy and as poor achievers compared to their peers which leads them to question their abilities. It is therefore important for role players to acknowledge that learners with dyslexia are not lazy, but that they have challenges in certain areas (Zambo, 2004). The resultant feelings and experiences of these individuals, which can be negated by those within their ecosystem, are shown in Figure 3.4.

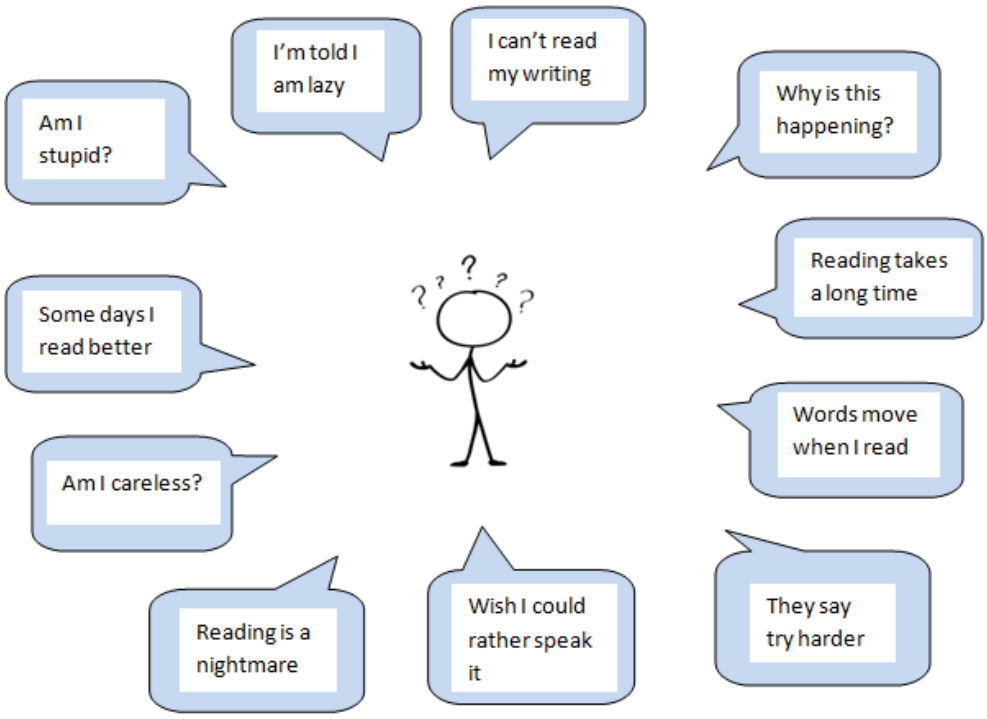


Figure 3.6: Feelings and experiences of those with dyslexia (adapted from Goodwin & Thomson, 2012)

The tactics used by those with dyslexia as the result of the emotional effects emulating from negative school experiences, are described as a lack of motivation, anxiety, avoidance of tasks, inattentiveness, disturbed sleep patterns, nausea, being subdued and withdrawn, frequent toilet visits, excuses to be out of the workplace and pretending to be tired or hungry (Casserly, 2013). Becoming the class clown, being impulsive, reacting emotionally and physically to peers who teased, a lack of self-control and anxiety are sometimes displayed by those with dyslexia (Stringer et al., 2011). Such reactions are suggested as stemming from accepting the diagnosis in a private capacity, whilst hiding it and finding it to be a problem at a public level, thus resulting in hostility (Riddick, 2010; Taylor et al., 2010).

3.4.1.3 Living with dyslexia

Living with dyslexia is a challenge that is faced on a daily basis. Despite the challenges posed, living a fruitful life is achieved by those with a strong support system, thus validating the important role of those in their ecosystem. Chu, Chung and Ho (2011) and Gur and Share (2011) attest to this wherein they state that challenges experienced are compounded when these individuals have no one to talk to. The transition from childhood into early adulthood is

described as a vulnerable period, as they are preoccupied with concealing their challenges, fighting for accommodations in secondary school and in jobs, as well as adapting to the demands placed on them in these institutions (Nalavany & Carawan, 2012). During this transition period, family support is critical and plays a valuable and protective role, as it is able to enhance self-esteem and encourage adaptive emotional qualities in these individuals (Nalavany & Carawan).

- **Everyday experiences of adults**

Dyslexia is not solely confined to life in the education domain, but is a learning challenge that affects the day-to-day life of adults. They indicate that they live with a constant awareness of the effects of the challenges posed as a result of having dyslexia; however, the understanding and support of those in their ecosystem is of great importance in assisting them to cope. Examples of the challenge faced daily involves the inability to read, which impacts on their ability to fill out various forms often required to be filled out by adults, including job application forms, thus having to depend on others and sometimes having to beg for help herein (Patton, 2015). Many indicate that they have good days and bad days, with tiredness often leading to a bad day which affects their reading ability and the time taken to complete tasks (McLoughlin et al., 2002). Therefore, some days require more attention than others and are hence more demanding. As a result, adults with dyslexia can be self conscious of their challenges resulting in them becoming vulnerable, concealing their dyslexia and showing extreme embarrassment when it is discovered (Alexander-Passe, 2015b).

Decisions to not reveal their dyslexia beyond education, is compounded by the stigma and ignorance surrounding dyslexia and this results in them hiding or camouflaging their challenges, as they fear that it will be placed on their record and thereby negatively affect job interviews which could improve career prospects and promotions (Alexander-Passe, 2015a). Pirttimaa et al. (2015) is of the view that disclosure must be carefully considered as it could result in negative labels, being thought of differently, being disempowered, facing more obstacles and sometimes the revelation is not necessary. Medical students indicated that revealing their diagnosis of dyslexia to peers resulted in social isolation where peers shied away from them because of not wanting to be with slow learners who would impede their progress (Romberg et al., 2016). These students further revealed that it was not only their school educators who treated them poorly because of their challenges, but also their medical school lecturers, who showed resentment, chastised them and saw them as making excuses. Some

students revealed that they did not disclose their dyslexia to university lecturers as they were concerned that they would be viewed negatively, have to defend their challenges, be stigmatised and perceived as being less able (Loveland-Armour, 2017). Based on these experiences, individuals with dyslexia should be protected by placing emphasis on their strengths, thereby creating a positive inner sense that is important for their well-being, and enabling them to learn to protect themselves from the misunderstanding and stigma associated with dyslexia (McNulty, 2003).

Identification of coping mechanisms ensures that secondary education and occupation choices are based on strengths, therefore scholastic subjects that require reading and writing are generally avoided and occupations that are in keeping with their strengths are chosen (Ingesson, 2007). However, despite making an informed choice, problems in the workplace are still encountered. Goodwin and Thomson (2012) list these problems as following stipulated procedures or orders in which things should be carried out, meeting deadlines, organisation and planning, coping with the workload, work based on literacy skills, concentration and the attitudes of work colleagues towards them. Dyslexia can therefore have a greater impact on employment than it has on education, in that various literacy skills remain the key requirements to most employment in the modern world (Macdonald, 2009). Further specific challenges in the job include filling in job cards/forms and writing work reports, and the inability to perform these tasks sometimes leads to embarrassment in the workplace (Patton, 2015). It is therefore not only reading skills that present challenges in adult life and in the workplace, but also writing skills which could negatively affect employment opportunities and creating anxiety when applying for jobs (Macdonald, 2009). Therefore, despite the prevalence of technology and irrespective of what career path is selected, most 21st century occupations require the skill of literacy (Bell, 2010). As a result fear, anxiety and not achieving what is within their capabilities in the workplace are often experienced (Alexander-Passe, 2015a) and this is compounded by the stigma of the learning challenge.

Stigma in the workplace was often described as caused by businesses and various institutions medicalising dyslexia and creating barriers to inclusion, resulting in a cycle of employment disadvantages for individuals with dyslexia (Bell, 2010). The attitudes and feelings towards those with dyslexia, using the lens of the medical model of disability is shown in Figure 3.2. Attitudinal barriers are caused by the belief that the person's abilities are solely defined by their dyslexia. Such experiences can cause embarrassment and a lack of confidence resulting in these

individuals not achieving what they are capable of, because of not applying for promotions or jobs that are within their competency (Bell, 2010). Bell further reveals that adults with dyslexia, who received accommodations such as technological support whilst still in education, experienced an increase in self-worth and achievement, thus increasing job opportunities, job satisfaction and their workplace coping mechanisms. In keeping with the social model of disability (Figure 3.2) assistance, support and the removal of barriers for those with dyslexia is of crucial importance for their success and self-fulfilment. A lack of support shown and an attitude that those with dyslexia have to take full responsibility to achieve, is related to the medical model of disability which many would like to believe is outdated. This proves that knowledge about dyslexia and change is not only needed in education but also in the workplace and in all of society.

Despite being discriminated against, many adults perceived their dyslexia and hence living with it positively by acknowledging that they are different and have unique skills of their own. This is attested to in Shaw et al. (2017) where dyslexia was attributed to the driving force for being a gifted educator, because of having the ability to simplify challenging concepts and being able to empathise with learners experiencing challenges. Adults, both in and out of education faculties, indicated positivity towards living with dyslexia and stated that even though they face challenges with reading, spelling and writing, they do not let it control their lives and hardly think about it (Ingesson, 2007). However, such positive feelings toward their dyslexia are not communicated by all. Horrible and unnecessary schooling experiences, have contributed to adults' feeling that dyslexia has made them feel unintelligent, lazy, and feeling that there was nothing positive about living with dyslexia (McLoughlin et al., 2002). Could this indicate the value of counselling, support and explaining what dyslexia is, in order to overcome their negative feelings, as referred to by Rose (2009)?

- **Relationships**

Very little research has been located regarding the effects of dyslexia on adult relationships. However, the limited research conducted thus far reveals that as a result of earlier negative experiences, adults with dyslexia lack confidence manifesting in a lack of social skills. Whilst they might have grown up with their challenges being understood by their parents and siblings who supported them as a result of understanding, this might change when they are adults, away from their family and in a relationship. They therefore experience the effects of their chronosystem. Many of the challenges faced in school are also faced in their adult relationships.

They often hide their dyslexia from their partners, as they fear that it will have a negative effect on their relationship in that they could be viewed as being abnormal, socially challenged or that they carry a challenge that is hereditary (Alexander-Passe, 2015b). Partners might be frustrated by the challenges observed which can include the inability to do simple tasks such as writing grocery lists, taking down messages or being forgetful, facing challenges in their careers and in the workplace and being unable to assist with their children's schooling (Alexander-Passe). This proves that the challenges of dyslexia do not only affect literacy, but can also have a negative effect on communication, relationships and adult family life as a parent. However, McNulty (2003) states that support and understanding from significant others plays a pivotal role in enhancing personal growth and thus improving the quality of adult life. The support and intervention provided from all their ecosystems impacts on these experiences and hence on their quality of life.

3.4.2 The impact of dyslexia on Maslow's Hierarchy of Needs

The experiences of individuals with dyslexia have a direct impact on the achievement of the basic, psychological and self-fulfilment needs located in Maslow's needs hierarchy. Fulfilment or partial fulfilment in each tier is required to move to the final tier which is self-actualisation; however, progression herein is not a constant and yo-yoing between the tiers can occur. The placement of these individuals in the hierarchy is greatly influenced by the ecosystems surrounding them; therefore, the needs of individuals cannot be discussed without the inclusion of their ecosystems.

The challenges of dyslexia can have a negative impact on the achievement of basic needs, which are found at the base of Maslow's hierarchy. These challenges often result in lifelong secondary consequences such as isolation and fewer career options, which could lead to impoverishment (Shaywitz, 2003), thereby affecting psychological needs and basic needs. Secondary challenges are often more difficult to overcome than the primary challenges and include a lack of confidence, low self-esteem, anger and frustration, anxiety, depression, social interaction problems and social isolation (Ebere, 2016; Rosetti & Henderson, 2013; Stampoltzis & Polychronopoulou, 2009). Ingesson (2007) is of the firm view that secondary effects are avoidable if the meaning and consequences of the diagnosis is explained to diagnosed individuals, their parents and educators, as this will enhance an understanding that the challenges refer to only one aspect of the diagnosed persons. Self-advocacy, self-acceptance and peer support have shown to assist in overcoming the secondary effects

experienced when living with a learning challenge (Rosetti & Henderson, 2013) thereby impacting positively on the attainment of needs. However, despite assistance that can be given by those in the ecosystem of individuals, research shows that secondary characteristics remain evident in the lives of many with dyslexia.

Failure is revealed as a common fear and being unable to acquire literacy skills at the same pace as peers leads to negative experiences, thereby impacting negatively on the emotions of individuals with dyslexia. Those with dyslexia have expressed that their fear of failure results in them becoming preoccupied with not failing, as well as being obsessed with how others view them (Meier-Hedde, 2011). This preoccupation and obsession negatively impact on the attainment of their needs. Disappointment is often experienced when failure occurs, despite working hard, and can result in feelings of sadness and being useless, which is further compounded when individuals have no one to talk to (Chu, Chung & Ho, 2011; Gur & Share, 2011), thus validating the important role of their surrounding systems.

The negative emotional effects experienced could be reduced if there was more understanding in what dyslexia is, as some people view it as a disease or medical condition, thus increasing the stigma that is attached to it (Rosetti & Henderson, 2013). This view is compliant with the medical model of disability. Dyslexia can therefore have a great impact on school life and hence school achievement, resulting in a low self-esteem which makes them feel inferior compared to their peers and viewing school as a place of torment (Ingesson, 2007). Focus on the attainment of Maslow's needs, will be directed to the self-esteem of individuals, which according to literature appears to be greatly influenced and thus affected by the challenges faced as a result of living with dyslexia. This need in turn impacts on the needs in other levels.

3.4.2.1 Dyslexia and self-esteem

Self-esteem is viewed by some as having a profound influence on a person's life, as it is a need that can affect the attainment of all needs on Maslow's Hierarchy. This trait is an important psychological construct that is surrounded in controversy despite the plethora of literature that exists herein (Bosson & Swann, 2009). Rosenberg (1979, p.260) refers to self-esteem as "a constant force" that affects motivation through, for example, feelings of inferiority, insecurity and not being loved, leading to discomfort, anxiety and feelings of being a misfit. Self-esteem is however, greatly influenced both internally by these individuals as well as externally by all the systems that surround them. With physical and intellectual development, constant

comparisons occur whereby the individuals measures themselves against/with others and interpretations of these measures as well as the interpretation of others' perceptions, have an influence on self-esteem (Burden, 2008). Low self-esteem is viewed as a key contributor to failure which leads to avoidance of challenges so as to evade failure, thus resulting in poor attainments that reinforces the feelings of being inferior and inadequate (Selikowitz, 2012).

Various descriptions and definitions of self-esteem are found where the wording is different but the meaning ultimately is the same. Rosenberg (1979) stated that it is a powerful human construct that refers to a person's internal feelings of self-respect which influences feelings of worth, and impacts on individuals' motivation to achieve. Bosson and Swann (2009) simply refer to it as the way that people evaluate themselves whilst Burden (2008) states that it is related to feelings about how individuals perceive themselves. Lawrence (2009, p.105) defines it as "the evaluation of the discrepancy between self-image and ideal self" and indicates that a link exists between self-esteem, academic achievements and behavioural problems. Armstrong and Squires (2015) indicate that it is an evaluation that individuals make of how they think they are, compared to their ideal view, of how they would like to be and is therefore the difference between the ideal self and the perceived self. Goodwin and Thomson (2012) describe it as being comprised of how we feel about ourselves, the judgements that we make about our value and these are influenced by our parents, home, peers, educators as well as society. Burden (2005) believes that past successes instil a positive self-belief and act as motivation to strive for future successes. Interplay is found between self-belief and self-esteem where they exert influence on each other. These constructs therefore interact, have a marked effect on each other and influence what is thus experienced by individuals thereby having an effect on identity. These constructs play a vital role in the lives of those with dyslexia throughout life both in education and in the workplace.

The negative effects that dyslexia has on self-esteem are referred to as taking place in a cycle where negativity results in further negativity, with the opposite occurring when positivity is experienced. This therefore has an effect on progression taking place between the Maslow's tiers in his hierarchy of needs. Osterholm et al. (2007) refer to the cycle that takes place between expectancy and stereotyping with that of being stigmatised, rejected and experiencing social distance. This can be seen where the inability to read can cause feelings of embarrassment and low self-confidence (Henry, 2015), and low self-esteem and social immaturity can result in being perceived as rejected or actually result in being rejected by others, thus leading to social

isolation (Selikowitz, 2012). Armstrong and Squires (2015) refer to the cycle wherein they indicate that it is created when experiences of failure lead to a reduction in attempting to learn or resistance to learning occurs, leading to the erosion of self-belief and hence results in a low self-esteem. The only way to fully understand and counteract the cycle and negative feelings associated with low self-esteem in those with dyslexia, is to gain a full understanding of the ways in which these feelings are manifested (Burden, 2008). If this is achieved, success will be experienced and will thereby act as motivation to achieve and be successful at more (Casserly, 2013), thereby instituting a positive cycle and upward movement on the hierarchy of needs.

Various feelings and effects on self-esteem are noted in those with dyslexia. It causes feelings of embarrassment, fear, shyness, loneliness, frustrations, confusion, lack of confidence and discomfort, with all being compounded by the system (educators, schools, peers) and thus leading to an erosion of self-esteem (Stampoltzis & Polychronopoulou, 2009). A negative self-esteem can result in negative physical reactions such as nausea, tremors and rapid heartbeats (Thomson, 2012). These reactions can lead to a lack of confidence in the ability to learn, feelings of inadequacy, feelings of failure, lacking the desire to learn something new, avoiding new learning experiences, low motivation, being anxious, insecure, becoming extroverted or introverted, reacting emotionally and believing that success is not possible (Lawrence, 2009).

Self-esteem is therefore negatively affected and decreased by failure, criticism, rejection and anything that has negative implications for individuals, whilst it is increased by possessing attributes that are socially desirable such as academic or social competence, being liked and being successful (Thomson, 2012). Feelings can be compounded negatively or positively by the reactions of others towards them (Taylor et al., 2010). Continually experiencing low self-esteem can present life-long challenges such as depression, negative mental health challenges (Pirttimaa et al, 2015). Low self-esteem can also lead to being suicidal, more likely to substance abuse, becoming school drop-outs or living in poverty as adults (Hurford et al., 2016). These dangers result from a build-up of emotional insecurity from the lifelong struggles experienced which leads to loss of self-esteem (Young Kong, 2011) and therefore negatively impacts all the needs of the individuals.

The education realm as well as the workplace can be challenging for those with dyslexia as a result of their struggles with literacy, thereby affecting feelings of self-worth and self-esteem

and impacting on achievement (Burden, 2008; Burton, 2004; de Beer, Engels, Heerkens, & van der Klink, 2014; Diakogiorgi & Tsiligirian, 2016; Humphrey & Mullins, 2002). Such negative feelings are often caused by barriers in the school environment that affect self-fulfilment (Claassens & Lessing, 2015), as well as by barriers faced in the workplace. The removal of such barriers is the aim of the social model of disability. Nalavany, Logan and Carawan (2017) in their exploration of the self-esteem of adults with dyslexia in the workplace, focused on three domains namely work attributes, work confidence and work anxiety. Results indicated negativity and discomfort arising from the workplace and it is suggested that if organisations are more accepting and supportive to those with dyslexia, this will result in a positive outcome for not only the individuals but also for the employer. In doing so, it will be a 'win win' situation for both parties.

- **Diagnosis and self-esteem**

Both diagnosis and therefore labelling, can affect self-esteem either negatively or positively. Glazzard (2010) is of the view that a positive self-image and hence positive self-esteem for those with dyslexia can be achieved if there is an early diagnosis of dyslexia and ownership of the label occurs. An early diagnosis and acceptance of the label can lead to positive self-esteem, as answers are provided for the challenges experienced thereby reducing feelings of humiliation, stress and anguish that learners with dyslexia often encounter (Humphrey, 2002). Early identification of dyslexia is therefore pivotal to providing the assistance needed and thereby developing a positive self-esteem, as those with dyslexia are at risk for developing a low self-esteem resulting from feelings of inadequacy when comparing themselves to others, being frustrated by the challenges encountered, feelings of failure, being anxious and battling to remain confident (Lawrence, 2009). Ingesson (2007) confirms this and states that the first six years of school are the worst for those with dyslexia as it negatively impacts on their self-esteem, therefore early identification and suitable interventions are imperative. She states that if the gap in ability widens, self-esteem and secondary effects are negatively compounded.

However, the value of an early diagnosis can only improve self-esteem if interventions and adaptations are put into place to assist these learners and thereby nullify the challenges experienced which could possibly lead to self-esteem problems (McNulty, 2003). It is important that those who are diagnosed are made to realise that the learning challenge is not only related to school and home but to everyday life, as it is always present and never outgrown (Rosetti & Henderson, 2013). Enhancing this understanding might prepare and empower these

individuals to work with their challenges, accept that it is never going away and this could assist with their self-esteem.

The effect that diagnosis can have on self-esteem (positive or negative) is influenced by various factors in the system, such as the attitudes of family and educators, the availability of supportive peer groups, the framing of the diagnosis, availability of technologies that can be of assistance to learning and the special talents that the individuals might have, which can assist in overcoming the academic challenges faced (Armstrong & Squires, 2015). Taylor et al. (2010) believe that increased social awareness of dyslexia, possibly from an increase in media coverage, has expanded the understanding of the specific difficulties experienced by those with dyslexia, that such persons also have strengths, can benefit greatly from additional help and support given to them in education and this understanding can increase the self-esteem of those with dyslexia. However, education about dyslexia needs to take place in the various ecosystems identified in Bronfenbrenner's EST. This need is attested to by adult dyslexics wherein they reveal that they, and hence their label, are stigmatised by the "non-learning difficulty population including their parents" (Macdonald, 2009, p.278).

- **The dyslexia label and self-esteem**

Labelling is viewed as impacting on the entire being of the labelled individuals, with its greatest lifelong effect seen on the effects that it has on self-esteem. It can affect self-esteem either negatively or positively and this is determined by individuals' internalisation of their perceived differentness, and the way in which they define themselves using the label as the criterion (Thomson, 2012). Perception of self is influenced by both internal and external factors which are interconnected, such as being aware of being different and also experiencing a change in the behaviours of others towards them as a result of the label (Savaria et al., 2011). The individuals' self-perception and hence self-esteem is therefore almost completely bound to the perceptions and reactions of others towards them (Osterholm et al., 2007). Thereby leading Arishi et al. (2017) to question whether labels actually assist individuals. However, the type of label and the labelling process appear to play a dominant role herein.

The labelling process can be formal where assessment is carried out by professionals such as psychologists, paediatricians and psychometrists, or it can be informal where labelling is done by lay persons including peers, with the latter referred to as providing informal labels. which could devalue individuals and have lifelong negative consequences on self-esteem (DeRoche,

2015; Thomson; 2012). Research indicates that the self-esteem levels of those with dyslexia are affected differently and by the particular label used. The specific label of dyslexia appears to positively enhance self-esteem because without this label, derogatory labels are often used, which impacts negatively on self-esteem (Hegstad, 2017). Taylor et al. (2010) concurring with Hegstad (2017) and Riddick (2000), found that children between the ages of eight and 15 with the dyslexia label showed a higher self-esteem than those with the general SEN label, indicating that the specific label positively affected their lives, home environment, schooling and relationships with peers. They reveal that this is however, influenced by the age at which labelling took place, revealing that the younger the individual, the more positive the results. Self-esteem can consequently be enhanced by a specific label as a result of it providing individuals with knowledge and understanding of why they experience their challenges (Boyle (2014). Providing the reason therefore, greatly contributes to understanding the challenge and thereby enhances self-esteem.

Understanding the label is therefore imperative to ensure that self-esteem is not negatively affected. Lawrence (2009) emphasises the value of explaining the diagnosis, the concept of dyslexia and hence the label to dyslexic individuals, as being identified with dyslexia, and given the label conjures up various unpleasant thoughts and feelings. Without an explanation, diagnosed persons could view themselves as being different or inferior to others who do not experience this learning challenge. Lawrence states that it is of utmost importance that there is an understanding by all role players that these individuals have strengths, that they can be taught to improve in the areas in which they experience challenges, and that such an explanation will prevent the label from being viewed negatively, as being an illness and thus negatively affect self-esteem. It is however, not just understanding but also participation in the construction of the label by those diagnosed, that appears to play a positive role in the self-esteem of individuals and leads to improved outcomes and participation in opportunities (Savaria et al., 2011).

Macdonald (2013) believes that with clear communication to ensure an understanding of what it is and what it means for their lives, the label can transform self-concept and self-esteem thereby negating the original belief of being intellectually restricted. This is proven in Karande and Sholapurwala (2011) where after the concept of dyslexia was explained to a ten year-old by both the educator and his mother, he accepted his diagnosis, was not ashamed of his challenges and spoke freely to his peers about his dyslexia. However, the opposite is found in

Stringer et al. (2011). A young learner was not provided with information about dyslexia, did not understand his challenges, questioned why he had what others did not have and felt strongly that he had to overcome it and not live with it. The importance of understanding is also indicated by a participant in Fairbanks (1992) in conveying his dyslexia story which included school experiences with the label. This participant indicated that he had no understanding of what the label meant apart from attending special classes that were referred to as 'dummy classes'. This term negatively affected his self-confidence, made him want to stay away from school because of the embarrassment and had a negative and destructive effect on his social life as making friends and accepting the fact that he was different to his friends was a major challenge. A lack of understanding is therefore detrimental to acceptance and thus impacts on the emotions of individuals which could have lifelong effects.

Acceptance of the label plays a vital role in self-esteem and cannot be achieved if the label is not understood. Damico et al. (2013) state that acceptance is the result of five stages. It starts from diagnosis, through to receiving the label, trying to understand it, functioning with it, through to viewing it positively, but acknowledges that few diagnosed individuals reach the positive stage even after a ten-year period. Higgins et al. (2002) name these stages as awareness of their academic and non-academic differences, the labelling event, understanding and negotiating the label, bracketing/compartmentalising their challenge and finally, transforming their negative attitude regarding their limitation into a positive. Achieving this could lead to appreciation of the challenges and the effects that labelling has had on them as individuals. This appreciation is observed in Anderson and Meier-Hedde (2011) where young participants expressed contentment with their challenge and indicated that they would not wish to be any different, or for their dyslexia to go away. Ingesson (2011, p.96) attests to this where acceptance resulted in a learner revealing his dyslexia to friends, "I told them myself, that feels good". His feeling were validated by his mother who stated that the diagnosis, label and acceptance made her son more relaxed, increased his confidence and most importantly being aware that he was not less intelligent than his classmates. Prior to the diagnosis and label, he felt that he was stupid, resulting in low self-esteem.

Low self-esteem is often experienced by those with labels. Labelling can result in making individuals feel different as a result of the intervention that follows the labelling process. It frequently leads to the placement of learners into ability groups, which could lead to the labelled learners being ridiculed and teased as underachievers by those learners in the higher-

achieving groups, thus creating self-esteem problems (Arishi et al., 2017; Fairbanks, 1992). Labels are extremely influential in that they can lower both the learners' and the educators' expectations and goals for what can be achieved in the classroom and can also create a sense of learned helplessness which can lead to low self-esteem, resulting from feelings of being unable to do well or being stupid (Kivi, 2015). However, not being labelled can also decrease self-esteem and lead to an increase in negative attitudes on the personal stigma scale, which is comprised of feelings of shame, discrimination, perceptions of status, and questions surrounding the place occupied and role played in society (Hegstad, 2017).

Therefore, care and respect should always be exercised at all times towards the use of the label, how the label is used, and consideration given for the feelings of the labelled person. Labels should never be used as an indicator of the full identity of the person. Arishi et al. (2017) state that this will have a detrimental and damaging effect on the self-esteem of persons who are totally identified by their label, as in the case when educators, practitioners or even society does not use the name of the labelled person but might refer to them as the 'dyslexic person'.

3.4.2.2 Systems involved in building the self-esteem of those with dyslexia

Those involved in building the self-esteem of individuals who are diagnosed with dyslexia, are found in the microsystem, mesosystem, exosystem and macrosystem. Whilst all people face challenges, those with learning disabilities face added challenges and stressors from family, schools and communities which impacts on their emotional and social outcomes (Morrison & Cosden, 1997) and hence their self-esteem. Environmental factors and barriers to learning that are experienced by those with dyslexia, contribute to an increase in the effects of stress, damaged self-esteem and fears of failure (Bell & Tudhope, 2016). It is for this reason that the social model of disability is advocated, so as to remove all barriers to learning.

Low self-esteem however, does not only have lifelong effects on individuals but also affects family, peers and society as a whole (Taylor et al., 2010). These effects are interactional. It influences a person's participation in society (World Health Organisation, 2011) and therefore a low self-esteem results in a loss of the person's contribution to society. This could be avoided if families, schools, educators and peers provide an environment that is friendly and accepting (child feels valued and secure), and that provisions are made to meet the needs of such learners (Humphrey, 2002). Support therefore plays a key role in building a positive self-esteem. Berk (2009) states that a warm parental relationship, social support experienced outside of the

immediate family, as well as community resources and opportunities afforded to the individuals, all assist in building positive self-esteem. This corresponds with Arishi et al. (2017) who state that self-image is developed and affected from interaction with others within a socio-cultural environment, with the ideal self referring to what the person would like to be and a high self-esteem being the driving force for goal achievement.

- **Parents**

Parents are usually closest to the child and therefore important role players in influencing the self-esteem of the child, and hence the self-esteem of adults. Low self-esteem that results from the negative emotional experiences encountered as a result of dyslexia can be positively affected with the support of family (Carawan et al., 2016). Jordan, McGladdery and Dyer (2014) concur and state that parents influence their children genetically, socially and psychologically, therefore their influence plays a crucial role in the development of the child. Parents should do their best to build their children's self-esteem as a means to create a cycle of success, which can be achieved by encouraging their children to believe in themselves and have faith in their abilities, as success will increase feelings of self-worth (Selikowitz, 2012). Goodwin and Thomson state that parents not only play an important role in building and developing the self-esteem of dyslexic children but also in helping them to recover from a low self-esteem, which will increase their resilience into adulthood. However, this can be a challenge for parents as Multhauf, Buschmann and Soellner (2016, p.1203) state that "parents of children who have dyslexia experience more parenting stress and depressive symptoms than other parents".

Despite this, Morrison and Cosden (1997) view good verbal skills, an understanding of the challenges faced, together with good parenting as being the key characteristics of enhancing the self-esteem of children. The role of parents in building the self-esteem of their children was confirmed in the study of Rosetti and Henderson (2013), as well as in Stampoltzis and Polychronopoulou (2009) where all participants indicated that their self-esteem was enhanced from the support, understanding, assistance with homework and help from parents. Families who show unconditional acceptance, love, support, interest and belief in their children contribute to their children accepting their challenges, having a high self-esteem and to becoming successful (Grimes, 2009). This could lead to achieving self-actualisation.

Parents can also negatively impact their children's self-esteem particularly if children are aware of their parents' anxieties and worries about their literacy challenges (Armstrong & Squires, 2015). Even though many of the case studies conducted in Anderson and Meier-Hedde (2011) faced various forms of adversity in that they were teased by peers, ridiculed, abused by educators and received little to no support from some educators in their first few grades at school, they showed strength in their self-esteem which is attributed to the care and support received from their families, particularly their mothers. Parents enhance their child's self-esteem by accepting and respecting the child's challenges, showing unconditional love, encouraging the setting of realistic goals to contribute to success, allowing them to make choices, providing them with opportunities to become self-reliant, emphasising the child's positive attributes, praising them for their efforts, teaching the child to praise themselves when achieving and encouraging the child to join social groups and thus have a feeling of belonging (Selikowitz, 2012). Ironically parents will be unable to do this if their own self-esteem is low therefore it is important that the parents of children with dyslexia are positive and have a high self-esteem (Selikowitz).

- **Peers**

Peers are also pivotal role players in the system. Those with dyslexia form perceptions of their peers feelings towards them, with this being an important component for the psychosocial well-being of those with the label of dyslexia (Hegstad, 2017). Peers referring to them as stupid, retarded, making fun of them, and teasing them, can lead to feelings of being stupid, self-conscious and having nightmares (Higgins et al., 2002). These researchers state that such experiences negatively affect the whole being of those with dyslexia, and can result in antisocial behaviour including aggressiveness and the belief that they are nothing more than the label. These negative experiences can result in feelings of isolation, being introverted and lead to absenteeism (Kivi, 2015).

Children do not want to be seen to be different to their peers and continually make comparisons with their performance against that of their peers (Armstrong & Squires, 2015). As a result of falling behind and not being on par with the other learners in the class, some with dyslexia experience being bullied and physically abused by peers (Gyarmathy, 2011). However, the policies of Hungary have much to do with this negative treatment of those with dyslexia, as dyslexia in this country is viewed as a mental illness. Viewing dyslexia as such increases the negative stigma associated with it, thus validating the impact of these individuals'

macrosystem. Some learners with dyslexia experience isolation and hence being ostracised because of being unable to follow and remember the rules of games played at school, which impacts on self-confidence and causes a lack of self-esteem resulting in emotional, social and educational effects (Jakubowicz, 2016; Yildiz et al., 2012). All participants in the SA study of Claassens and Lessing (2015) were called names by their peers, they felt misunderstood and judged by them, and as a result of these perceptions, they faced socialisation struggles which impacted negatively on self-esteem. Such effects could be difficult to overcome and remain with these individuals from childhood into adulthood.

However, positive peer relationships and peer support is found and attested to in Anderson and Meier-Hedde (2011). Rosetti and Henderson (2013) refer to such support as occurring when those with dyslexia are surrounded by accepting and non-judgemental peers who provide them with the opportunity to talk about their challenges. This can be achieved if educators provide learners with the opportunity to work in groups as this will enhance both learning and social skills as well as self-esteem, as it provides such learners with the opportunities to discuss their challenges with those who face similar challenges (Burton, 2004).

- **Educators**

The lack of appropriate intervention and the negative attitudes shown by educators can result in feelings of being fearful, academic stress and a lower self-esteem (Meier-Hedde, 2011). Educators who are insensitive and humiliate learners with dyslexia by referring to their challenges or exposing them in the classroom, negatively impact on such learners' self-esteem whereas those who support, understand and accommodate such learners contribute to a positive self-esteem (Glazzard, 2010). Insensitive educators are referred to in Singer (2008) where students revealed that educators showed anger towards them for their slow progress, humiliated them in front of peers and this often led to them being teased and bullied. Not being protected and respected by their educators profoundly affected their self-esteem. Many negative educator experiences revealed by learners with dyslexia includes being called names such as lazy and stupid with these negative labels sometimes stopping once diagnosis had taken place, thus enhancing the prospect of developing a positive self-esteem (Humphrey, 2002).

Educator support can increase both the self-esteem and confidence levels of learners and lead to academic success (Casserly, 2013). Therefore, educators should listen to the learners and their feelings, they should reward them for effort and not for the work, they should not use

words that discourage or embarrass such learners, they should assist such learners to achieve realistic and attainable goals and most importantly all classroom instruction, routines and requirements should be carried out to assist these learners (Ebere, 2016). Educators' failure to do this is reflected in Wearmouth (2004) where a learner as a result of his despair caused by his educator, changed from feeling competent to incompetent, seeing himself as a poor achiever compared to his peers, feeling agitation and despair; however, he was able to change his negative feelings, become self-confident and is now a master's student in science and engineering. This was however, achieved because of other role players in his system who assisted with his esteem needs.

Armstrong and Squires (2015) suggest that the self-esteem of learners with dyslexia can be protected by educators who instil a positive class ethos where every child's abilities are valued, where learners are allowed to demonstrate to their peers their competence in activities and to avoid making belittlingly remarks about their literacy abilities. This is observed in Gur and Share (2011) where a learners' self-esteem was built in the fourth grade after facing challenging years at school, and this was as the result of being taught by someone who knew his needs, made the necessary accommodations, reduced the amount of homework, encouraged him and made him believe that he could be successful. The opposite however, is reflected in Yildiz et al. (2012) where educators are seen as being responsible for providing peers with the means to ridicule and make fun of the work produced by those with dyslexia, by asking peers to mark homework given. Hudson et al. (2007) state that without the appropriate intervention and programmes, learners with dyslexia are at risk for developing low motivational levels and that it is the duty of schools and educators to help such learners to understand their strengths and weaknesses and thereby increase their self-esteem.

- **Education Institutions**

The educational experiences of adults with dyslexia show that it has a lifelong influence on their emotional health and self-esteem, which therefore affects the way in which they adjust and function as adults (Nalavany, Carawan & Brown, 2011). School experiences often negatively affect the self-esteem of learners with dyslexia, as many feel isolated and excluded in their schools (Humphrey, 2003). Facing continual failure at school (Gyarmathy, 2011) especially where learners know that they are trying and can do better (Pirttimaa et al., 2015), negatively impacts self-esteem. The role of tertiary institutions is highlighted in Rosetti and Henderson (2013) where it is stated that a sound knowledge of dyslexia, which includes

knowledge of its scientific basis and symptoms, will improve the climate in the institution, remove the stigma shown and thereby improve the educational experiences for these learners and students and thus enhance self-esteem. Therefore, it is not only the educators who play a pivotal role in the self-esteem of those with dyslexia, but also educational institutions.

The ethos of educational institution towards those with dyslexia affects the self-esteem of these learners. Often educational institutions through various factors, create a negative climate for those with dyslexia (Kirwan, & Leather, 2011). The importance of the ethos of the institution is referred to in Burden and Burdett (2005) and Nalavany et al. (2011) where children and adults with dyslexia who attended specialist schools had a higher self-esteem resulting from a decrease in negative emotional experiences. This resulted from the understanding and support that was shown to them at school which increased their confidence in their abilities to achieve. This is confirmed in Nugent (2008) where the self-esteem of those in specialist schools were higher than those with dyslexia in mainstream schools where feelings of being isolated, rejected, teased, bullied by their peers and excluded academically, were experienced. Being happier and having a positive self-esteem in special schools results from being with peers who have similar challenges, feeling more comfortable and accepted as well as realising that some learners' challenges are greater than theirs (Casserly, 2013; Rosetti & Henderson, 2013).

Therefore, the educational setting should be suited to those with dyslexia so as to have a positive impact on their self-esteem (Jones & Heskin, 2010). This is highlighted in Wearmouth (2004) where learners were provided with the incorrect educational provisions which caused much frustration and had a profoundly negative influence on self-confidence. Incorrect provisions impede learning and the ability to negate or even overcome the challenges faced. Humphrey (2002) states that mainstream schools should create an environment where all learners feel valued and secure and their educational, social and emotional needs are met. Such an environment contributes to enhancing the self-esteem of all learners. Kirwan and Leather (2011) refer to adaptations that can be made in the education environment by referring to Socrates who did not write and made the necessary accommodations for his students who faced the same challenges as he did. He gave these students the opportunity to critically analyse their learning, their thinking and their understanding and present it in dialogue form through recordings.

However, Burden and Burdett (2005) question if mainstream schools can ever become dyslexia friendly as this will necessitate the development of whole school policies (macrosystem) that embraces an inclusive ethos where all can have feelings of self-worth. As yet this is not being achieved as whilst inclusion and equality in education is supposedly in place, many refer to the exclusion and prejudice they experience (Earey, 2013). Inclusive mainstream schools should provide the benefits delivered to learners with dyslexia by special schools, and this should be achieved by not only focusing on teaching but also in positive peer group interaction, as this could have a profound influence on their confidence levels of being socially accepted and thereby enhance their self-esteem (Nugent, 2008). Theoretically it might be possible, but it cannot be achieved in practice without transformation in all systems.

- **Society**

Social acceptance is central to human life for many and plays a pivotal role in affecting self-esteem. Such social acceptance is often dictated to by society's expectations and standards. This is especially challenging for those with dyslexia when society views literacy as a key for achieving educational and occupational success (Carawan et al., 2016; Nalavany & Carawan, 2012). Thomson (2012) states that when individuals behave in a manner that protects or enhances their self-esteem, it is done as an attempt to increase the way that others see their relational value, which thereby enhances social acceptance. Trying to improve their prospects of being socially accepted and hoping that others will see their value is a means to protect or enhance their self-esteem (Arishi et al., 2017). Many role players are involved in the person with dyslexia's feelings of being socially accepted. Lawrence (2009) is of the view that whilst it is recognised that educators play an important role in developing learners' positive self-esteem, parents play an even greater role herein.

The development of self-esteem is an important key for the child's future as a lack of self-esteem will result in an adult that will forever view their academic ability and hence life negatively, whereas a good self-esteem will result in an adult that is able to cope with life irrespective of the academic challenges and limitations (Selikowitz, 2012). The self-esteem of those with dyslexia will continue to be at risk as long as society continues to place emphasis on linguistic abilities and sees it as a determinant for achievement (Lawrence, 2009). Self-perception and hence self-esteem has a marked influence on academic success and success in life in general (Humphrey, 2002). Therefore, it is the duty of parents, educators, peers and societies to support those with dyslexia and equip them to utilise strategies to protect their self-

esteem as all people want to feel good about themselves (Singer, 2008). However, low levels of academic expectation shown to those with dyslexia by parents, siblings, educators, schools and society lowers the self-esteem of these individuals and increases anxiety and insecurities (Young Kong, 2011).

3.5 CONCLUSION

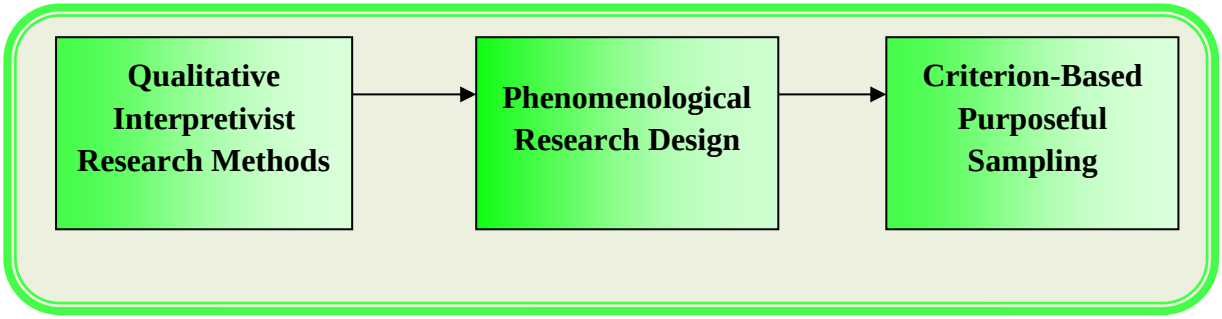
The effects of dyslexia and labelling on the experiences of those diagnosed and hence living with this label, are largely impacted on and influenced by the various role players found in their surrounding systems. These role players do not only influence the experiences of those with dyslexia, but they also play a key role in the motivation and achievement of the needs identified by Maslow. Failure to diagnose individuals and a lack of education for all about dyslexia, results in continued stigmatisation and ignorance which negatively impacts all areas of the individuals' lives.

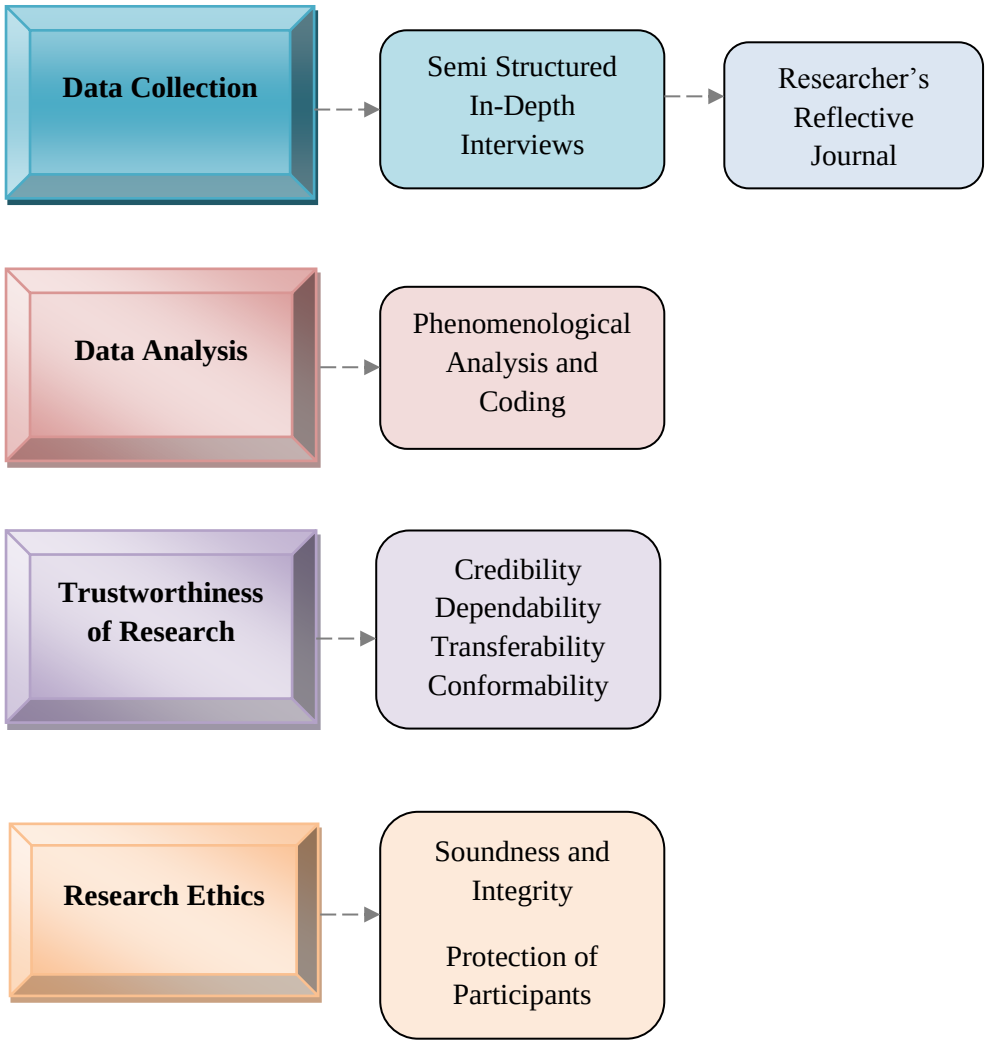
An understanding family, caring educators, peers who show sensitivity and a society willing to embrace all persons and recognise that all are different are reflected in this chapter as essential in the life of the person with dyslexia. Little research situated in South Africa has been discussed in this chapter and no South African study has been located that addresses the feelings of persons with dyslexia towards the label, thereby substantiating the importance and need for this study.

CHAPTER 4

RESEARCH DESIGN AND METHODOLOGY

OVERVIEW OF THE CHAPTER





4.1 INTRODUCTION

The aim of this study was to gain insight into the views of those living with the label of dyslexia, and thereby acquire an understanding of their lives through personal descriptions given. The literature review conducted in Chapters 2 and 3 revealed that there are differing views and perceptions about dyslexia and labelling, which in turn are impacted and influenced by the various ecosystems that surround those living with dyslexia. This chapter provides and discusses the research paradigm as well as a detailed description of the research method, research design, sampling strategy, methods used for data collection, analysis and interpretation. Reasons for the choices made are provided and discussed. The research ethics followed to ensure that the study is ethically sound are described, as well as the steps observed and implemented to ensure the credibility and trustworthiness of the study.

4.2 RESEARCH PARADIGM

Guided by the research questions, the selected frameworks and the research design of the study, an interpretivist paradigm was selected as appropriate to explore the lived experiences of adults living with dyslexia. Various factors contributed to the selection of this particular paradigm, with the main factor being that the paradigm selected had to be one that was closely linked to phenomenology. The use of phenomenology as the research design was selected from the outset of this study, as it was viewed as essential for negating the researcher's possible bias that could occur. As interpretivism is influenced by phenomenology, an approach that places emphasis on considering the subjective interpretation of people and their perception of their lived worlds to understand the phenomena (Maree, 2016), it was deemed most appropriate as the guiding paradigm of this study. Therefore interpretivism and phenomenology guided the interpretation of the views and meanings of the phenomenon as described by the research participants, thus leading to the findings of this study

Interpretivism, like phenomenology, is grounded in the world of lived experiences, thereby enabling an understanding of how others view their worlds and make sense of the contexts in which they live and work (Christiansen, Bertram & Land, 2010). The interpretivism paradigm is based on the belief that human life can only be understood from within, that social life is a distinctive human product with the human mind being the source of meaning and that human behaviour is affected by what is known of the social word (Maree, 2016). Therefore, through the use of interpretivism, meanings of the experiences of others can be constructed (Maree, 2016).

Interpretivism places emphasis on the uniqueness of individuals thus enabling them to provide their own interpretations of their own experiences (Cohen, Manion & Morrison, 2011). As dyslexia is a phenomenon that is socially constructed and therefore interpreted differently by individuals, this unique interpretation results in multiple realities (Creswell & Poth, 2018). The phenomenon and environment is explored, from the perspective of those who live in it and all constructs of the phenomenon are important (Schram, 2006). The interpretivist paradigm therefore recognises that individuals differ from each other despite experiencing the same phenomena, which in this study is dyslexia. Using this paradigm, rich description of events and issues surrounding the described experiences of dyslexia were provided. The researcher was able to capture and convey what the participants thought and felt together with the reasons for these thoughts and feelings. Denzin and Lincoln (2018) view this as an advantage that is not offered in quantitive research.

The aim of interpretivism is therefore to understand the way in which individuals create, modify and interpret their world (Cohen, Manion & Morrison, 2011). The researcher's focus was not directed at predicting but rather at describing how individuals make sense of their worlds and how they "make meaning of their particular actions" (Christiansen, Bertram & Land, 2010). Therefore, the role of the researcher was to understand and explain the experiences explored, using the perspective of the participants. Through the use of interpretivism, the participants described their experiences of living with the label of dyslexia, and provided the researcher with insight into these lived experiences.

4.3 RESEARCH METHOD

Guided by the research question asked in this study, a qualitative research method was essential to guide the research. This research method was a vital component of a study, as it assisted in the planning of the research and provided a grounding within the selected conceptual and theoretical models (Lichtman, 2014). The suitability of qualitative research for this study is provided by Marshall and Rossman (2016, p.2) who state that it is "pragmatic, interpretive and grounded in the lived experiences of people", with it historically being used "to explore, explain or describe a phenomenon", thus making it suitable for discovering the unexpected and exploring new areas. A comprehensive definition of qualitative research is provided in Creswell and Poth (2018, p.8), who retain the definition given in Creswell (2013, p.44):

> Qualitative research begins with assumptions and the use of interpretive/theoretical frameworks.....addressing the meaning individuals or groups assign to a social or

> human problem.... using an emerging qualitative approach.... the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes. The final report... includes the voices of the participants, the reflexivity of the researcher, a complex description and interpretation of the problem, and its contribution to the literature....

The aim of qualitative research is "to describe, understand and interpret human phenomena, human interaction or human discourse", where phenomenon refers to the lived experiences of people, interaction refers to the way in which people interact with each other, and discourse refers to the way in which people communicate with each other, with all often being influenced by culture (Lichtman, 2014, p.38). It illuminates meanings, captures stories to understand the perspectives, context and systems in which the participants are found, identifies unexpected consequences, enables comparisons to be made and leads to the discovery of patterns and themes (Patton, 2015). The researcher can therefore discover and describe narratively, the meaning of people's lives by looking into their beliefs, interests and the meaning that they attach to their actions (Erickson, 2018). Qualitative research offers a direct and hence personal experience, that enables the researcher to get close to people and circumstances, it is interactive and intersubjective, sensitive to the context, as well as interpretive and selective (Schram, 2006).

Qualitative research looks for insight into the question 'what' (implicit or explicit) and 'how' in an attempt to gain an understanding of the context, consequences or outcomes, and it also explores the significance of what is being investigated in the bigger picture of the world (Wertz et al., 2011). Therefore, this method will permit my research to be conducted within the selected frameworks of this study namely, Bronfenbrenner's Ecological Systems Theory and Maslow's Hierarchy of Needs. It will enable the participants to describe their experiences of living with the label of dyslexia and provide answers to the 'what' and 'how' questions. As qualitative research draws attention to understandings and practices that are implemented and accepted as correct (Wertz et al., 2011), the findings of this study, through the descriptions provided, can provide insight into the current practice in SA which often avoids the label of dyslexia. As revealed in the literature review, this practice appears to emanate from secondary persons (those who have not been diagnosed with dyslexia), with little input obtained from those who are diagnosed with dyslexia.

As qualitative research attempts to discover and understand the meanings of experiences from the perspective of the person experiencing the phenomenon, data is collected directly from such persons (Bloomberg & Volpe, 2016). Multiple methods of data collection can be used, thus enabling the study to be one that is emerging, evolving and interpretive (Marshall & Rossman, 2016). As a result of its ability to evolve during the research process, it is dynamic and fluid (Lichtman, 2014) and allows the design and or focus of the study to be modified during the research process Maxwell (2013). It is therefore a method that is not fixed and can be changed.

The researcher, whose voice was used in the study, was the main instrument of enquiry and was therefore central to the entire research process by gathering data, examining the collected data, constructing meaning by interpreting interviews, observing and looking at documents to find meaningful patterns (Bloomberg & Volpe, 2016; Lichtman, 2014; Patton, 2015). Lichtman describes the researcher as being the eyes, mind and lens for all ideas, interpretations and plans, with the lens being the mental filter that could affect interpretations of the data collected and thus reported in the study (Yin, 2011). Researchers can enter the real world of the participants, delve into the phenomenon being researched through the use of open-ended questions and provide detailed descriptive data, that assists in not only providing an understanding of the individual, but also an understanding of the system that of which the individual is a part (Patton, 2015). Descriptions take place through what was perceived and thus interpreted (built on factual claims) by the researcher, who makes use of various senses based on what was seen and heard (Schram, 2006). Whilst qualitative research is particularistic, thus making it difficult to generalise the findings to broader conditions beyond that of the present study conducted, the value of the research is increased if findings can be generalised and conclusions are found that have implications that go beyond that of the data collected (Yin, 2011).

4.4 RESEARCH DESIGN

The research design is identified as the plan that will be followed for conducting the study and should provide the methods that will be used to answer the research question (Bloomberg & Volpe, 2016; Maxwell, 2013). It therefore addresses the topic studied, defines the entire structure of the study, guides the researcher to make selections based on that which strengthens validity, and ensures that data is collected and analysed accurately (Lichtman, 2014; Marshall & Rossman, 2016).

The selection of the research design is therefore one of the most important choices made, as it must provide valuable insight into the research question. As many different types of research designs exist, much reflection and thought is required to ensure the selection of one that is most appropriate. Patton (2015) however, points out that despite the care taken to select an appropriate research design, no perfect design exists, and that compensations always have to be made regarding the number of questions in the interview schedule, breadth versus depth (how much time will be spent trying to fully understand the person's experiences), and whether literature should be reviewed before, after or during data collection. Bearing these factors in mind a phenomenological research design was selected as best suited to guide this study and provide insight into the questions asked.

4.4.1 Phenomenological Research Design

The main purpose of phenomenology is to investigate and provide insight into the 'lived experiences' of individuals, and thereby identify the core essence of the experience or phenomena being described (Bloomberg & Volpe, 2016). Husserl, a German mathematician, coined the term 'lived experience' which he called 'Lebenswelt' (Husserl, 1969). He referred to the 'life-world', as the world of living experience that comprises the "pre-given, familiar, present, available surrounding world" that includes both 'nature" and "culture" (Moran, 2012, p.6). Based on this idea of Lebenswelt, a phenomenological study can be described as one that enables the description of the common meanings shared by participants' of their lived experiences (Creswell & Poth, 2018) and resists making prior categories that could distort the basis for understanding the phenomenon studied (Yin, 2011). No adding or subtracting of information occurs, therefore information collected is unaltered (Giorgi, 2009).

Phenomenology empowers the researcher to "methodically, carefully and thoroughly" describe peoples experiences, how they perceive, describe, feel, judge, remember and make sense of it, thereby gaining a deeper understanding of the phenomenon (Patton, 2015, p.115). Insight into lived experiences occurs through direct contact and interaction with the research participants, therefore attentive listening, observations, and the refinement of the representations of the created experiences occurs, with the researcher being mindful of personal biases (Bowie & Wojnar, 2015). Finlay (2013, abstract) identifies phenomenological research as comprising of (a) attitude, (b) entering the lifeworld (through descriptions of experiences), (c) dwelling with horizons of implicit meanings, (d) explicating the phenomenon holistically and (e) integrating frames of reference".

A transcendental phenomenological approach, originating from Husserl (1859-1938), is used in this study to describe and provide credible findings of the participants' subjective and hence lived account of their experiences of living with the label of dyslexia, as well as the impact that it has had on their needs. Husserl embraced two procedures as being necessary for the study of human experience and a tool for eliminating or negating bias, and referred to them as the epochés of the natural sciences and the epochés of the natural attitude (Wertz, 2005). The Greek word epoché, meaning abstention, is central to phenomenology and sets it apart from other methods (Schram, 2006; Wertz, 2005). Epochés assist the researcher to achieve an unbiased attitude during analysis (Lichtman, 2014), as it enables the bracketing of the researcher's acknowledged preconceived ideas and judgements (bias), thus creating distance during analysis by allowing the researcher to focus solely on the essence and meanings of the experiences (Schram, 2006). This process involves the "deliberate suspension of judgement" passed by the researcher through noting and setting aside all personal views of the phenomenon, prior to the commencement of the study or especially prior to the literature reviews (Lichtman, 2014, p.115). Wertz et al. (2011, p.125) identified the process as:

- The first epoché involves making a note and setting aside of natural scientific knowledge that exists about the research topic prior to investigation. Prior knowledge that could influence the results of the investigation is bracketed and continually reflected on during the investigation of the phenomenon to ensure that there is no influence from prior work and knowledge.
- The second epoché is sometimes referred to as 'phenomenological reduction' and here "the researcher abstains from the natural tendency of consciousness to unreflectively posit and focus on the existence of objects independent of experience".

In the final description all data, noting the researcher's bias and experiences with the phenomenon, are used to provide new insights and understandings of the phenomenon (Nelms, 2015). Yin (2011) however, feels that the final analysis of the data remains a challenge for the researcher who has to avoid portraying his/her own research lens, therefore the goal should be to acknowledge that multiple interpretations could exist, thereby preventing the researcher from imposing his/her own interpretation of the participants' views. Yin further states that such acknowledgement makes the qualitative researcher a relativist (multiple realities) and not a realist (single reality); however, most qualitative researchers place themselves along a continuum between that of relativist and realist. Phenomenology, together with the selected frameworks, forms the back bone of this study, as they will be the guide in all choices made

and hopefully reveal the researcher's position on this continuum. Following a phenomenological research design, I elucidate the research methods used which includes how the sample group was obtained, the research instruments used, the transcription of each interview and finally the analysis of the data collected.

4.5 SAMPLING

The sampling approach used plays an important role in both the quality and validity of the study, with the choice herein based on four key factors, namely the sample size, representativeness and parameters of the sample, access to the sample and the sampling strategy that will be used (Cohen, Manion & Morrison, 2011). Decisions have to be made about who should be in the sample, the form of sampling to take, how many people will be sampled and if the sampling is consistent with the qualitative approach selected for the study (Creswell & Poth, 2018). Such decisions were impacted by constraints that included time, accessibility and expenses involved which impeded the researcher gaining information from a bigger population. Sampling in this study took place using the guiding principles of that suited to a phenomenological study.

4.5.1 Sampling procedures

Purposeful sampling was selected as most suited for obtaining the participants in this qualitative study. Creswell and Poth (2018) state that purposeful sampling occurs when individuals are selected to be participants because they can purposefully provide information related to the phenomenon in the study. This type of sampling enabled the researcher to select and study a small number of cases who are "information rich" thereby enabling the researcher to gain in-depth insight and understanding which can come from a small number of participants (Patton, 2015, p.46). Through the participants selected, the researcher gained insight into the research question asked, as well as insight into the central phenomenon of the study (Creswell & Poth, 2018), which is living with the label of dyslexia. However, it was imperative that the selection of participants should be based on the expected richness of information that they could provide, and therefore to not only support the researcher's views, but also to challenge these views (Yin, 2011). Maxwell (2013) stipulates the goals of purposeful sampling as:

- Achieving representation for the individuals being studied;
- Capturing the diversity (heterogeneity) of the population of individuals being studied;
- Enabling comparisons to be made regarding the differences between individuals; and

- Selecting participants with whom a relationship can be developed and who will be the best to answer the research questions and thereby provide the best data for the study

The form of purposeful sampling employed in this study was criterion based. A criterion-based sampling strategy is suitable when the participants studied are representative of others who experience the same phenomenon (Bloomberg & Volpe, 2016). The criteria used in this study to select research participants are:

- They must be formally diagnosed with dyslexia by a professional who is qualified to make the diagnosis;
- Diagnosis could occur whilst in school, in tertiary education or even as adults;
- Be between the ages of 18 and 40;
- Be able to communicate in English;

There are no hard and fast rules with specific numbers in qualitative studies, as the size depends on the purpose of the enquiry, the insight to be gained, and ensuring a credible study within the available time as well as the resources at hand (Patton, 2015). As the goal of qualitative research is to collect extensive detail about each person studied (Creswell & Poth, 2018), the sample used is typically small, and often consists of fewer than 10 participants as the aim is not to generalise but to describe and interpret (Lichtman, 2014). Focusing on a small number of participants enables an open-ended exploration where the data collection is deeper and detailed (Creswell, 2016). Once sufficient data has been collected that assists with the understanding of the phenomenon being studied, the sample size is viewed as adequate (Lichtman, 2014); however, it is imperative to justify the size of the sample used, as it affects the credibility, trustworthiness and transferability of the study (Marshall & Rossman, 2016).

The sampling procedure in this study commenced with a multistage or clustering procedure referred to in Creswell (2014), whereby the researcher requested assistance from a third party (an association) to provide the names of individuals who satisfied the criteria of the study and who might volunteer to be possible participants (Appendix B). Therefore, bearing in mind that the researcher did not have direct access to the names of all possible participants and was reliant on a third party, as well as complying with the research design of the study, the researcher aimed to have a minimum of six and a maximum of 10 adult participants. As this study is

located in SA, diversity based on both gender and racial ethnicity was noted and considered, so as to increase the representativeness of this study.

Of the 10 participants who, through the director of a dyslexia association, consented to the release of their contact details to the researcher (Appendix D), eight consented to being participants in the study (Appendix F). Having a small number of participants (eight) is in keeping with phenomenology (Groenewald, 2004). It was advantageous as the researcher was able to create depth and develop relationships with each participant (Marshall & Rossman, 2016). Further the individuality of each research participant was preserved during the analysis phase, unlike studies that have large numbers and aggregate the findings (Maxwell, 2013). The demographics of the eight participants, who formed the sample group in this study, are indicated in Table 4.1.

Table 4.1: Demographics of the sample (adapted from Bloomberg & Volpe, 2016)

Pseudonym	**Gender**	**Present Age**	**Schools attended**	**Education**	**Occupation**
Jane	Female	20	Mainstream public, Independent and Home-School Centre	Grade12 One year psychology course (tertiary)	University Student
Kim	Female	30	Mainstream public and special school	Grade 12 Tertiary education (Honours degree)	Personal Gym Trainer
Clive	Male	37	Mainstream public and special school	Grade 12 Graphic Design Course	Graphic Designer
Shana	Female	38	Mainstream public	Grade 10 Printing College course	Restaurant Manager
Walter	Male	33	Mainstream public and public technical	Grade 10 Software Quality Analyst (Computers)	Software quality analyst.

Henry	Male	26	Independent	Grade 12 BSc Mechanical Engineering	Student and Tutor Master's in Mechanical Engineering
Stacey	Female	28	Independent	Grade 12 Bachelors degree in Psychology and Chefs course	Chef on private yacht
Mary	Female	18	Home Schooling	Grade 11	Grade 12 learner and entrepreneur

All participants in this study had never been provided with the opportunity to describe their dyslexia experiences. This concurs with Creswell's (2016) view that the value of qualitative research is that not only does it enable the study of sensitive topics, but it can "lift up the silenced voices of marginalised" persons who are often sidelined in conventional research, resulting in little being known about them.

4.6 DATA COLLECTION STRATEGIES

As data is the foundation of a study (Yin, 2011), in that it is used to answer the research question and achieve the aims of the study, the selection of appropriate data collection methods was imperative. Previously qualitative data was derived from four basic types of information namely, interviews, observations, documents and audio-visual materials; however, new forms have emerged with the assistance of technology such as e-mail, web-based interviews, chat rooms, weblogs, internet and message boards (Creswell & Poth, 2018). These new forms have resulted in data that is diverse in that it includes written, graphic, auditory, artistic, kinaesthetic as well as verbal data which discloses the lived experiences of the research participants (Wertz et al., 2011).

Husserl (1969) advocates interviews, field notes as well as descriptive essays as suitable research instruments in a phenomenological study. Therefore, guided by this, two instruments of research were selected to obtain the data that is relevant for this study namely, interviews and the researcher's personal journal. I would have liked to have had a participant's diary but a written record would have been a challenge given their literacy challenges.

4.6.1 Interviews

In a qualitative study, interviews are often selected as the main means of collecting data because of its ability to provide rich insight and descriptions that have depth (Bloomberg & Volpe, 2016; Johnson, 2017). Interviews are referred to as conversations conducted for a purpose (Brinkmann, 2018), involving at least two people, and requiring the art of asking questions, listening to the answers and producing text that is negotiated (Denzin & Lincoln, 2018). Interviews provide the words of the individual's personally experiencing the research question, and portray "real people, real events, real experiences" (Rubin & Rubin, 2012, p.60). Interviews can be "one-on-one" where the researcher and participant are physically in the same room, or it could be "face-to face" where technology such as a phone or computer video calls are used (Creswell & Poth, 2018, p.164). Therefore, interviewing with the use of technology is advantageous if the participants cannot be easily accessed; however, face-to-face verbal interviews are preferable as they provide mutual contact, context sensitivity and conversational flexibility (Brinkman, 2018).

The purpose of the interview is to gather relevant information from the participants for the study. Structured, semi structured or in-depth dialogue encourage the participants to reveal their feelings, experiences, ideas or thoughts by answering the questions asked in the interview (Lichtman, 2014) thereby leading to the researcher's interpretations (Creswell & Poth, 2018). To achieve this end, the topic had to be viewed as important and central to the lives of the participants (Rubin & Rubin, 2012) and it was imperative that the researcher created an environment where the participant felt comfortable, as this encouraged dialogue (Creswell & Poth). The interviewer's approach conveyed to the participants that their views were of value and hence useful, as the data obtained depended on both the researcher and participants' attitudes in being willing to participate in a deep discussion (Seidman, 2006; Marshall & Rossman, 2016). It was important that the interviewer showed empathy, openness, sensitivity, respect, neutrality, was mindful of time where the interviews were not too drawn out, and was aware that the quality of the data obtained was dependant largely on the interviewer (Patton, 2015).

4.6.1.1 Semi-structured in-depth interviews

Bearing in mind that the process of collecting data in a phenomenological study is mainly comprised of in-depth interviews (Creswell & Poth, 2018), such interviews were selected as the main method for data collection. It is a fairly simple method for obtaining data and allows

for close and personal interaction between the researcher and participant, with the aim of providing insight into the research question (Marshall & Rossman, 2016). Whilst face-to-face interviews were preferred, where both parties are physically in the same room, Computer Assisted Personal Interviewing (SKYPE)[5], as well as WhatsApp Video Calling were also carried out as a result of participants not being in close proximity to the researcher.

The method of interviewing selected was in keeping with the choices made by the participants, thus ensuring that their convenience was always noted and accommodated. However, all participants located in a 70 kilometre radius from the researcher were interviewed face-to-face. I was mindful that interviews had to be conducted in a location that enabled a private conversation, and where there were no distractions (Creswell & Poth, 2018). Of the eight interviews conducted, four were face-to-face, three were SKYPE and one was via a WhatsApp video call. This "one-point-in-time approach" enabled individual interviews per person, wherein data was obtained and comparisons across the various participants made, thus allowing the study to occur in a narrow time frame (Patton, 2015, p.255).

4.6.1.2 Interview questions

In keeping with phenomenology, the questions asked during the interviews were aimed at providing the researcher with insight and understanding into the participants' experiences of living with the label of dyslexia. Maxwell (2013) and Lichtman (2014) state that well constructed and focused interview questions usually result from an interactive design process, where the purpose and research question dictates the content of the interview questions. Therefore, bearing in mind that the participants were the true experts of the experiences, focus was placed on the main research question and aims of the study, as answering this question and achieving the stated aims was dependant on the quality of the interview questions. Further, it was imperative that the researcher was knowledgeable about the topic being studied and that good questions were asked to ensure a fruitful conversation where the required and necessary data were collected (Yin, 2011). Therefore, an intense literature review was carried out in Chapters 2 and 3 of this study.

[5] SKYPE is having an internet picture conversation with another person using software that enables it, therefore it permits face-to-face interaction and interviews even though the researcher and the participants are in different geographical locations (Lichtman, 2014).

Questions asked in the interview were compiled from the start of this study and throughout the writing of Chapters 1 to 3. These questions were guided by the frameworks of the study and focused on the participants' experiences of dyslexia and the label of dyslexia, within the context of their families, schools, peers, community, in the workplace and in adult relationships. Included were questions about the effect that dyslexia has on the attainment of needs. Following the recommendations of Rubin and Rubin (2012) that detailed data go beyond the surface and examine the layers beneath it, the interview guide consisted of main questions to provide a platform for the interview. This ensured that all areas of the research were included, and that all research questions were answered. I was aware that questions based on concrete or particular experiences were more likely to elicit detailed experiences than general questions (Johnson, 2017).

Questions asked encouraged the research participants to reveal their world. Therefore, it was imperative that the participants understood what was being asked, that the researcher knew when to ask follow-up questions, to probe for greater depth and detail, and thus practised the art of listening and hearing during the interview, as this would affect the quality and meaningfulness of the responses given (Patton, 2015). Further, it was crucial that the researcher was fully prepared for issues that might develop, and have the skills to ask follow up questions, or to know when to ask the participant to elaborate (Marshall & Rossman, 2016), especially if the participant was not talkative or not providing sufficient information (Johnson, 2017). However, when using probes, the researcher was mindful that responsive interviewing is gentle, cooperative, respectful and ethical (Rubin & Rubin) and to always remain neutral and ask questions that are not biased (Lichtman, 2014).

A semi-structured or guided interview with a general set of questions found in the Appendices and was followed as a form of guidance and used on all the participants. Doing so ensured that sufficient questions that were central and relevant to the topic being studied were asked (Yin, 2011). Following these questions assisted in time management during the interview by ensuring that questions were kept within the boundaries of the study and that sound questions were asked (Creswell & Poth, 2018). Having an interview guide (Appendix G) ensured that the researcher was respectful and courteous to the participants in that questions were pre-planned. Despite having the interview guide, questions varied according to the situation, with the aim of encouraging the participant to share in-depth information and enhance the researcher's understanding (Johnson, 2017; Lichtman, 2014). The interviewer was therefore not bound to

pre-set questions and had the freedom and scope for following up on questions that were regarded as important (Brinkmann, 2018).

Semi-structured interviews were not limiting for the data collected and allowed the participants to provide more depth in their responses about their experiences, opinions, perceptions and feelings (Patton, 2015). Focus was placed on past experiences, present experiences and a combination of both to describe the individuals' experiences of the phenomenon being explored, thereby describing the meaning of a concept that is shared by individuals (Seidman, 2006). Bearing in mind that research participants might not be open to revealing and articulating their feelings, experiences and perceptions (Bloomberg & Volpe, 2016), questions asked about an experience were varied (the same question asked but phrased differently). However, the researcher was of the view that all participants tried to answer the research questions to the best of their ability.

4.6.1.3 Interview procedure

When scheduling the interview, researchers should open their schedules to accommodate the availability of the participants, and the location selected should be based on privacy, noise and comfort levels, especially for the participants (Johnson, 2017; Lichtman, 2014). The interviews conducted herein took place at a private venue and at a time selected by the participants. Following the advice of Seidman (2006), interviews were not longer than 90 minutes to show respect for the participant's available time. Seidman (2006) further cautioned that longer interviews could negatively impact the research, by affecting the confidence and anxiety levels of the research participants. As interviewing and listening carefully, as well as making notes can be mentally challenging and cause fatigue (Yin, 2011), the researcher scheduled interviews with sufficient time in-between to assist herein.

To gain the cooperation of the participants and increase their willingness to share personal information, it was essential that the researcher developed a rapport with the participants to show herself as approachable and someone with whom the participants could feel comfortable and accepted (Lichtman, 2014). After prospective participants agreed to the release of their contact details, the researcher contacted each participant telephonically with the aim of introducing herself and verbally informing them of the study. Therefore, an introduction and rapport had been developed with all participants prior to the interview.

Before commencing with the interview, all cell phones were turned off to limit or curtail disruptions that could affect the interview (Yin, 2011). Interviewing started with a general conversation, wherein the researcher thanked the participants for consenting to be a part of the study. Thereafter, the study was discussed including aspects of confidentiality and privacy, as well as the right to withdraw. After participants indicated that they did not have any questions regarding the study, interview questions were asked. This was not done in a way to influence the responses that were going to be given to the questions asked or to deceive or pressure the participants, but solely to achieve a trusting relationship that would enable open, honest and detailed replies to questions asked (Rubin & Rubin, 2012).

The interview followed a conversational mode of inquiry which presented a two-way interaction where the research participants felt free to question the researcher, thus leading to a sort of individualised social relationship with each research participant (Yin, 2011). The researcher was however, mindful that whilst the relationship should be friendly, it was not a friendship (Seidman, 2006), and that the researcher should not appear as domineering or manipulative (Johnson, 2017). Even though an interview guide was followed, the verbalised questions for each research participant differed according to the context and setting in which the interview took place (Yin, 2011). The researcher was mindful of the following guidelines provided when conducting the interviews:

- To speak in modest amounts and less than the research participants;
- To read and listen between the lines;
- To ask questions that would encourage a longer dialogue, to give the participants the opportunity to reflect on their experiences, to never interrupt the participants whilst talking and never complete a sentence or phrase for a research participant who is struggling or pondering the right words;
- Always ensuring that the participant had sufficient time to collect their thoughts, prepare for the response to be given and thus respond to a question before asking another;
- To avoid questions that appear to interrogate;
- Maintaining composure, showing an interest in the participants' answers which are often personal in nature and respecting their beliefs and viewpoints, as this could lead to more information being provided by the participants;

- Analysing during the interview as a means of determining whether follow-up questions should be asked, or probes used but be mindful of being content with the responses and not over probing;
- Staying neutral with regards to body language, expressions, tone and words which could convey biases thereby impacting on the answers given, as this could result in the participants telling you what you want to hear (Creswell & Poth, 2018; Johnson, 2017; Rubin & Rubin, 2012; Yin, 2011).

Notes were made during the interview as it assisted with the flow of the interview and helped if the train of thought during the interview was lost (Rubin & Rubin, 2012). These notes also assisted with concentration, and helped the researcher to not interrupt the interview process (Seidman, 2006). Notes enabled the researcher to formulate new questions as the interview progressed. These questions were used to check something said earlier, assisted with later analysis and provided backup in the event of the audio recorder malfunctioning or if the recorded interview was erroneously erased (Patton, 2015). A template based on the interview guide (Appendix G) was used by the researcher to record notes made during the interview. The template further prevented any distractions that could be caused to the researcher during this process. As recommended by Creswell and Poth (2018) sufficient space was left between each question thereby enabling the researcher to return to questions previously asked and which might have been further explained or described as the interview progressed. Notes made during the interview had shortcuts in the form of shorthand, acronyms and abbreviations; however, the accuracy or precision was not impeded by this (Yin, 2014). To ensure a successful interview, the researcher maintained eye contact with the participant to ensure that the non-verbal responses given by the participants were observed (Johnson, 2017). Each interview concluded with the participant being thanked for affording the researcher with the opportunity to interview them and for giving of their time.

On the day following the interview, WhatsApp messages were sent by the researcher to each participant, thanking them for the interview and indicating that follow-up interviews might be needed to clarify points or expand on what was described (Creswell, 2016). All interviews were conducted within 90 minutes; however, all follow up information needed by the researcher was sought and provided via WhatsApp messages both typed and audio.

4.6.1.4 Data recording

Each interview was recorded to provide an accurate record of what transpired, thus ensuring that analysis was based on all that was given in the interview, as well as enabling the exploration of different interpretations and perspectives (Rubin & Rubin, 2012). These recordings were therefore vitally important, as they captured the actual words of the research participants and provided the raw data which were the actual quotations spoken by the participants (Patton, 2015). However, the researcher was mindful that despite their importance, data recording techniques should not be obtrusive, and participants should never be asked to slow their talking (Yin, 2011). Audio recordings of the interviews were the main source of data collection for this study and were supplemented by note taking (researcher's reflective journal).

To accurately record the research participant's perspective, good high quality recorders were essential (Creswell & Poth, 2018; Patton, 2015). Two digital recorders were used for each interview in case the one failed, and recordings were carefully marked at the completion of each interview. The researcher mastered the use of the devices to prevent any distractions, as this could negatively impact on the conversation and the viewing of researcher's abilities by participants (Yin, 2011). Prior to each interview, both recorders were tested, thus ensuring that they were in working order, and to circumvent the rescheduling of the interview because of equipment malfunction (Johnson, 2017). Fresh batteries were placed in each recorder and spare batteries were on hand (Rubin & Rubin, 2012). At the beginning of each interview, consent for the recording was sought from the participants (Yin, 2011). Following the advice of both Johnson (2017) and Seidman (2006), audio equipment was only switched off when all conversations had ended, as valuable information could have been gained during this time if questions were asked or the conversation continued. On completion of the interview, the digital recordings were marked, checked, notes were added to and then packed away. A record of the length of the interview and the start and stop times was made.

Reviewing the interview was critical, as it was a time for reflection, elaboration and provided quality control thus ensuring that the interview provided the needed data, therefore interviews were scheduled with time period between them (Patton, 2015). Immediately after the interview, the researcher checked that the recordings were successful, or if certain things were confusing therefore requiring the researcher to contact the participant to ask for clarification (Patton, 2015). Listening to the tapes soon after the interview, stimulated the recall of non-verbal language used such as certain facial expressions and body language (Yin, 2011). It also enabled

the evaluation of the questions, as it revealed whether different questions, better questions or follow up questions should be asked, and therefore the changes that should be made to subsequent interviews (Johnson, 2017; Rubin & Rubin, 2012). Despite in-depth interviewing assisting the researcher to describe the deep meaning of the experiences explored using the words of the participants, interviews were further supplemented with a further source of data collection, thus increasing the validity of the study (Marshall & Rossman, 2016).

4.6.2 Researcher's reflective journal

The researcher's reflective journal was a valuable source of data in the study and was comprised of the notes made by the researcher, personal thoughts about the research, as well as the researcher's observations and personal reflections gained during interviews. This journal addressed issues in the study, reflected on aspects in the research process, showed the researcher's thinking, methods of working, dilemmas faced, observation notes, notes of thoughts and insights gained (Johnson, 2017; Marshall & Rossman, 2016; Lichtman, 2014). Continuous insight into the thinking of the researcher was provided as this journal was on-going from the beginning of the research. The researcher's emerging ideas, records of what was happening in the research, personal feelings, persons spoken to when making major decisions, reactions to others, feelings experienced during interviews such as tense, relaxed, or friendly were recorded in this journal (Rubin & Rubin, 2012). Notes were descriptive and reflective, where in-depth descriptions of participants behaviours and interactions were noted, thereby enabling the researcher to reflect, explore and examine the researcher's experiences and beliefs in relation to that of the research participants (Johnson, 2017).

In keeping with the principles of phenomenology, and therefore applying the first epoché, the researcher's bracketed assumptions and preconceived ideas about dyslexia and the label of dyslexia, were continually recorded in this journal. This assisted in ensuring that the true essence and meanings of the experiences were reported on free of bias, or having noted the researcher's bias. Even though audio recordings were made of each interview, the researcher was mindful that the answers provided by the participants went beyond the verbal responses given. Therefore, notes about observations made during the interview were included in the researcher's reflective journal. As participants might differ in the directness of their answers and hence not being straight to the point, it was of utmost importance that the researcher listened intensely, was observant, watched body language, mannerisms, intonations and energy

levels and made notes based on the inner voice messages received whilst listening (Seidman, 2006).

Observations about the participants' intentions or deeper meanings in what was being conveyed were recorded in this journal (Yin, 2011) as soon as was possible after each interview. Notes written therefore included the researcher's thoughts and reactions (Lichtman, 2014). All notes made were then read with the aim of filling in the gaps, adding to them, and ensuring that the shorthand used was understood. Therefore, notes made were enhanced and a narrative of each interview was produced. Marshall and Rossman (2016, p.221) emphasise that the researcher's reflective journal is valuable as it can change the analysis of the data "from mundane and obvious to the creative", as the researcher puts together a story of behaviours and sentiments that will be used as building blocks during the analysis phase of the research.

4.7 DATA ANALYSIS

Data analysis commenced with ensuring the protection of all data collected. This was achieved by organising all data, making duplicates of the digital recordings of the interviews, making notes in the researcher's journal, and storing the original and duplicate copies in separate places (Yin, 2011). Duplicates of the digital recordings were saved onto a USB Flash Drive as well as onto a computer external hard drive. As recordings produce huge volumes of information, transcribing it is a time-consuming procedure that should take place as soon as possible (Johnson, 2017). As the transcription of a 30-minute interview could result in 20 single-spaced pages, the need to work with a small number of participants was validated (Creswell, 2016).

Even though the task of data analysis is complicated as well as daunting, the transcription process is made extremely difficult if data is left to accumulate (Maxwell, 2013; Yin, 2014). It is however, beneficial for researchers to transcribe their own recordings, as it increases familiarity with the interview data, brings the interviewer closer to the data which could reveal nuances and assist with the analysis phase (Creswell, 2016; Rubin & Rubin, 2012). Being mindful of the above advice, all recordings were transcribed using Sonix, a software program; however, accuracy herein was limited. Corrections were personally made by the researcher to the software transcriptions, which required the researcher to carefully listen to the recordings Transcriptions were done verbatim, thus including non-verbal communication such as pauses, laughter and interruptions (Bloomberg & Volpe, 2016).

After the transcriptions of the audio recordings were completed, and copies made of each transcription, the researcher was faced with the challenge of analysing the data from each transcript. As data analysis takes place in a particular context and not in a vacuum (Wertz et al., 2011), all data analysis for this study used the principles of Husserl's transcendental phenomenology, in order to answer the research question asked. Describing the experiences of those living with the label of dyslexia without any bias, it was essential that the researcher based the analysis on Husserl's principle, that the information was allowed to impart this description, thus allowing the data to speak for itself. To achieve this, the researcher had to assume the correct psychological attitude towards the data, which included the attitude of phenomenological reduction and showing sensitivity to the phenomenon being investigated (Giorgi, 2012). This attitude was shown throughout the analysis of the data, wherein all potential biases, past and present were recognised continually to obtain a bias-free analysis (Giorgi, 2008), with the researcher always being mindful of both epochés. Figure 4.1 outlines the process used in the analysis of the data in this study, obtained from the transcriptions of the interviews as well as the researcher's reflective journal.

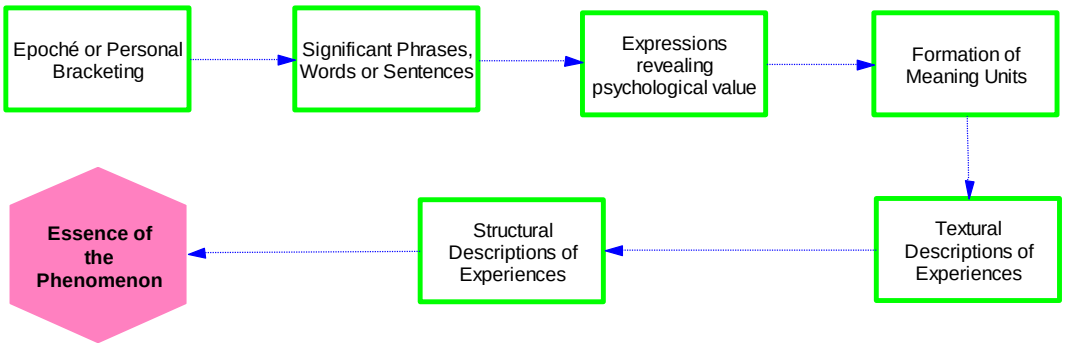


Figure 4.1: Flowchart for data analysis (adapted from Creswell & Poth, 2018, p.217).

Phenomenological reduction commenced at the start of the study with the formation of the first epoché containing the researcher's bracketed views and hence biases that were continuously added to throughout the duration of the study. After data collection, phenomenological reduction continued wherein the second epoché was employed. This epoché was imperative to allow the researcher to reflect solely on the lived world of the participants through the descriptions imparted by them (Giorgi, 2008). The researcher therefore approached data analysis with a mind that can be likened to a 'clean slate'. The phenomenon was concentrated on solely based on what was described by the participants, therefore refraining from all non-given knowledge (Giorgi, 2012).

Data analysis was guided by the phenomenological analysis steps and coding described by Creswell and Poth (2018), Giorgi (2012) and Lichtman (2014). The researcher read all the transcripts several times to increase familiarity with it, thereby commencing the process of making meaning of it. Transcripts were read holistically where the expressions of the participant that were relevant to the questions asked by the study were followed. By reading each transcript repeatedly, through the descriptions given, a clear picture of the lived world of each research participant was developed. During this phase, the researcher was mindful of personal biases both past and present, the necessity to ensure an open mind and not to have an aim, agenda or make judgements. Aware of the epochés and showing sensitivity, all significant phrases, words or sentences from each transcript were identified and noted using the words of the participants. These were written in the researcher's reflective journal. This provided an audit trail of the entire coding process, enabled the researcher to refine the codes and indicate all thoughts about the relationships among codes, thus leading to clustering the codes into categories and themes (Yin, 2011). Phrases, words or sentences were revisited and turned into expressions revealing the psychological value of what the participants had said.

Through interrogation of the expressions, meaning units or themes were formed by condensing repeated or overlapping statements. Meaning units were grouped into broader units of information thus providing the basis for interpretation. By reflecting on the psychological significance of each meaning unit, a textural description of 'what' was experienced was provided. Direct verbatim examples or quotes from the interviews were used to provide the textural description. Thereafter, a structural description of 'how' the experiences happened was drawn up through the researcher reflecting on the setting and context in which the phenomenon was experienced. The structural description occurred within the framework of the ecological systems described by Bronfenbrenner. The final analysis provided a composite description of the phenomenon that included both the textural ('what') and structural ('how') descriptions thus providing the 'essence' of the experience, as depicted in Figure 4.1.

4.8 TRUSTWORTHINESS OF THE RESEARCH FINDINGS

Trustworthiness refers to achieving a study that has integrity and therefore, one that readers will believe and trust (Schram, 2006). Lincoln, Lynham and Guba (2018, p.122) refer to the trustworthiness of a study as embracing “goodness or quality criteria”. This is achieved through validations wherein the researcher indicates the measures taken to ensure the “accuracy” and hence validity of the study (Creswell & Poth, 2018, p.259), thereby indicating that the study is

"believable, accurate and plausible" (Bloomberg & Volpe, 2016, p.164). Therefore, commencing from the proposal stage, the research design should show a stipulated plan for the measures that will be followed to address the trustworthiness of the research (Marshall & Rossman, 2016).

Lincoln and Guba (1985) addressed the trust and transparency of qualitative research by asking questions revolving around the criteria used to judge the credibility of the study's findings, the evidence produced for the findings and evaluating the evidence as authentic and true. These researchers' constructs of attempting to ensure authentic findings are credibility, transferability, dependability and confirmability, and even though these constructs date back to their 1985 book, they repeat it in later editions of their writings. Lincoln and Guba's constructs are still widely used by many researchers today and applied in this study together with the phenomenological research design, to validate the findings. Using the research design is important to ensure validity (Yin, 2011), as it assisted in negating results or conclusions arrived at which might be incorrect (Maxwell, 2013).

4.8.1 Credibility

Credibility refers to the measures taken by qualitative researchers to demonstrate that their data is accurately represented. The credibility of the study had to be addressed throughout the study from the proposal stage right through to the end of the research, and it was imperative that the research design selected was one that enhanced credibility (Marshall & Rossman, 2016). Key validity threats in qualitative research are researcher's bias which is the subjectivity of the researcher, as well as reactivity which is the effect that the researcher might have on the participants (Maxwell, 2013). Credibility can be achieved through self- reflection and constant monitoring, wherein the researcher identifies and eliminates subjective bias and perspectives, uses multiple sources of data to check interpretations and looks for various ways in which the data could be understood (Bloomberg & Volpe (2016).

Research integrity is essential as it validates whether the study can be trusted as representing the truth, therefore it was imperative that the researcher disclosed as much about the methodology that could affect the study and the outcomes (Yin, 2011). The credibility of the study was therefore in the hands of the researcher, who as the primary instrument of data collection, had to show competence and thoroughness to uphold the value of the study (Patton, 2015). The voice of the researcher had to be credible and produce findings that conveyed

authenticity and trustworthiness (Patton). To ensure credibility and the negation of bias, the principles of phenomenology were strictly adhered to.

Credibility in the study was further enhanced through triangulation. Creswell (2016) refers to triangulation as the use of multiple data sources to obtain evidence that leads to the eventual themes in the study. Marshall and Rossman (2016, p.262) define triangulation as "the act of bringing together more than one source of data to bear on a single point", thereby strengthening the findings of the study through the use of more than one source of data collection. It often involves the use of different types of data about the same information, thus making the findings of the study more believable and acceptable (Lichtman, 2014). A perspective is gained from different levels, thus going beyond the knowledge from one approach (Flick, 2018). Therefore not relying on a single source, provides a more valid understanding for the conclusions arrived at, thus increasing the credibility and strength of the study, as multiple data sources can be intersected or cross checked to substantiate the findings (Johnson, 2017; Maxwell, 2013; Yin, 2011). All data sources were compared (Patton, 2015) thereby increasing convergence between the sources resulted in stronger findings (Yin, 2011).

To increase the credibility of the study, triangulation of data occurred through the use of interviews and the researcher's reflective journal. The challenges experienced as a result of their dyslexia and time constraints as adults, prevented the keeping of a participant diary. It is however, important to note that credibility is not only derived from who is interviewed and checking different data sources, but it is also obtained from how carefully the study is carried out, thus achieving convincing evidence for the conclusions drawn (Rubin & Rubin, 2012).

4.8.2 Transferability

Transferability is a form of external validity that refers to the extent to which the findings of the study, if repeated with other participants or in other contexts, are applicable or can be useful to theory, future research or to practice (Lincoln, & Guba, 1985). Whilst the goal of qualitative research is not to generalise, it aims to achieve transferability where the findings can be applied, fitted in or be of value to similar contexts or settings (Bloomberg & Volpe, 2016). The construct of transferability therefore refers to whether the findings are only applicable to the present study or will other similar studies have the same findings (Marshall & Rossman, 2016). Transferability can be achieved if the study is built on strengths and has solid findings (Patton, 2015).

Bloomberg and Volpe (2016) state that through the provision of rich detailed descriptions and information, a holistic representation or portrayal of the findings results, thereby increasing the transferability of the study. However, Pandey and Patnaik (2014) view transferability as a challenge in qualitative research, because such studies are specific and use small sample groups, therefore making the findings applicable for the particular context. Nevertheless, Lincoln and Guba (1985) are of the view that the challenges posed by small sample groups regarding transferability, is negated if sufficient data is obtained. Therefore, it is important that the researcher reveals the extent to which the findings can be transferred and its possible relevance to other contexts (Moon, Brewer, Januchowski-Hartley, Adams & Blackman, 2016).

To ensure transferability, first conclusions arrived at must not accepted; data must be re-examined, alternative conclusions and rival explanations must be explored, conclusions arrived at debated and any doubts and weaknesses must be acknowledged (Paton, 2015). Transferability in this study was achieved by:

- Providing and describing the personal and observed details of the research participants;
- Providing and describing the context in which the participants' experiences were set;
- Providing supported evidence for the findings through the use of direct quotes from the data sources.

Ensuring the above, determined if the findings of this study can be transferred and used by others in a similar context.

4.8.3 Dependability

Dependability refers to measures taken to determine and thus ensure that the findings of the study will be consistent if the study is repeated with the same participants in the same context (Lincoln, & Guba, 1985). It therefore refers to the findings being consistent and reliable if repeated with the same or slight alterations to the sample and context. Various techniques can be employed for establishing the dependability of a study.

Bloomberg and Volpe (2016) refer to an audit trail which keeps track of the procedures used in data collection and interpretation, where detailed specifics are provided on how the data was collected and analysed, as well as having the codes and findings checked by a colleague. Memoing in the researcher's reflective journal provided a measure of dependability. This

memoing provided the audit trail during the various analysis phases of all ideas and key concepts arrived at, thereby assisting to track and reflect ideas (Creswell & Poth, 2018). This assisted in evaluating the accuracy of the interpretations, providing others with insight herein, and showing whether the findings were supported by data (Pandey & Patnaik, 2014), thus providing transparency into the data analysis procedure (Rubin & Rubin, 2012). In this study, my supervisor checked the findings so as to adhere to the ethical requirements of my study.

4.8.4 Conformability

Conformability refers to whether the findings of the study can be reproduced in another study or confirmed by another person, how the inferences made by the researcher will be understood by another, do the inferences make sense, can concrete proof be provided, can the findings be argued and are the findings transparent for others to see (Marshall and Rossman (2016). These criteria refer to the extent to which the findings of the study are a true reflection and not influenced by the researcher's bias (Lincoln, & Guba, 1985). Verification of findings in phenomenology cannot be achieved using independent persons or even the participants, as such verification should occur by checking phenomenological procedures which are unknown to others outside of the study (Giorgi, 2008). Giorgi further states that the experiencer (the researcher) is the best judge of the meaning of the experiences explored. Therefore, researchers must ensure that the findings are the result of the experiences of the participants and not based on the researcher's preferences (Pandey & Patnaik, 2014). As conformability is affected by bias, which the researcher brings into the study emanating from the researcher's background and identity, it must be eliminated through the selected design (Maxwell, 2013).

The research design should reveal the various steps taken by the researcher to ensure that the findings are unbiased and can be confirmed by others. The first step observed in this study to eliminate or negate researcher bias and obtain objectivity, was the formation of epoché 1. Here the researcher bracketed all possible biases consisting of assumptions and preconceived ideas formed prior to conducting the interviews, thus allowing the researcher to remain impartial to the data collected. The researcher was able to enter, reflect and describe the lived world of the research participants, solely based on that which was given by the participants during data collection (Wertz, 2005). Epoché 1 was accounted for throughout the data analysis procedure of this study. The audit trail in the researcher's reflective journal further enhanced the conformability of this study. This journal provided a record to all that was done and derived, therefore providing transparency to the study. Being precise, staying close to the data and

stipulating which terms and words belong to the participant and researcher, provided evidence for conclusions reached (Rubin & Rubin, 2012).

4.9 RESEARCH ETHICS

The principles and practices of sound research ethics is central to the value of a study, therefore, a stipulated plan for the ethics that will be followed to address the absolute protection of the participants must be provided (Marshall & Rossman, 2016). Even though intrusiveness in phenomenological studies are minimal (Creswell & Poth, 2018), the researcher had to anticipate all risks that could occur. Failure to identify possible risks and follow good ethical practices can negatively affect all aspects of the research including the protection and rights of the participants. Ethical issues in research occurs prior to conducting the study, at the beginning of the study and during data collection (Creswell, 2016). All were noted from the outset of this study.

Obtaining university approval for the study to be conducted was sought after the researcher had worked on the first three chapters of the study. However, it is important to note that this approval was sought prior to making contact with possible participants and therefore prior to data collection. Knowledge gained during the writing of these chapters and the ethical plans that were determined as necessary for the study, enabled the completion of the required detailed ethical clearance application form. Here the researcher outlined the value of the study as well as the sound research ethics that would be followed and observed. This application was in the form of a detailed proposal that was submitted to the University of South Africa's Ethics Committee, from whom ethical clearance for the study was sought. This committee provides the code of conduct required and monitors all research conducted in the institution, to ensure that sound ethical practices are followed and adhered to by researchers. Emphasis in this application was placed on whether the study was viable, how it would be conducted, a description of how participants would be approached, as well as the measures that would be taken to ensure the utmost protection of all participants. The study met with approval and an ethical clearance certificate (Appendix A) was issued. This certificate granted permission for the study to proceed. Therefore, after receipt of this certificate, the process of finding research participants for the study commenced.

In ensuring ethical soundness and ethical integrity, the researcher adhered strictly to the ethical standards stipulated in the ethical clearance application, regarding the procedure to be followed

to obtain the names of possible participants. Gaining access to individuals who satisfied the research criterion of the study involved several steps. As the researcher did not have direct access to the names of suitable persons, assistance from a third party (an association) was sought to identify persons who satisfy the criteria of the study. To ensure anonymity, no indication is given herein about the third party; however, this was provided to the ethics committee and is also known to the supervisor of this study. A three-step ethical procedure was carefully followed to gain access to the contact details of possible participants.

The researcher personally met with the third party and provided three letters to the said person:

i. A letter that described the study and included a request made to assist in providing the contact details of possible individuals who complied with the criteria of the study. Persons approached by this third party were given two letters:
    - An information letter describing the study and requesting consent for personal contact details to be given to the researcher; and
    - A letter where individuals who were approached, provided signed consent for the release of their name and contact details to the researcher.

All of the above-mentioned three letters are found in the appendices.

As all participants in this study were older than 18 and hence adults, their consent was the only consent sought. After ensuring that the above ethical procedures were duly followed, the names and contact details of possible participants were provided to the researcher. Telephonic contact was then made with these persons to enable the researcher to explain the study and request their email addresses if they showed interest in being a participant in the study. A letter, similar to the first letter received from the third party, as well as a consent form was emailed to each person (Appendix E and F). Of the ten persons contacted, eight agreed to participate in the study and signed the consent form prior to being interviewed. Consent was given by these eight participants without any coercion and with them being aware that participation was voluntary and that they could withdraw at any time. The three information letters in the Appendices indicated:

- the purpose for conducting the study;
- what participation in the study involved (interviews and audio recording);
- the potential benefits of the study;
- confidentiality and anonymity of identities of participants was promised;

- voluntary participation - participants were allowed to withdraw from the study at any stage;
- that the services of a psychologist was available, if needed; and
- the identity and contact details of the researcher and supervisor.

4.9.1 Protection of participants

Human participants must always be protected (Murray & Beglar, 2009) and methods to be employed in the study ensured this, as it was an important component of the ethical application made to the ethics committee of the university. Careful attention has to be paid for the protection of all who participate in a study and an ethical clearance certificate will not be issued if appropriate measures to ensure this are not revealed in detail. Risks to research participants included psychological damage, therefore the researcher had to account for how this would be prevented (Yin, 2011) and ensure that promises made to the participants about their protection were never violated (Rubin & Rubin, 2012). Three ethical principles guide qualitative ethical research namely:

- respect for the participants wherein their privacy is protected, and consent is obtained from them to participate in the study:
- concern for their welfare is observed wherein they experience no harm where their information is shared with others:
- justice is provided where they are treated fairly and never deceived (Creswell & Poth, 2018).

When making contact with the participants, the researcher was clear, honest and transparent about the purpose of the study, explained the benefits of participating, did not make promises that would not be kept, assessed the risks involved if any could arise from the interview and indicated how it would be handled (Patton, 2015). This was done both verbally and in writing. As confidentiality and anonymity are essential for the protection of the identity of the participants and to ensure their trust placed in the researcher, the promise to not reveal their names was upheld (Creswell, 2016). To ensure this, it was important that the researcher disguised the names of the participants as soon as possible, to circumvent situations where the participants' names might be revealed in the data analysis and the findings (Creswell & Poth, 2018). Participants' names were replaced with a pseudonym, with the actual name of the participants only known to the researcher.

Respect is an important factor that is necessary for ethical research. Respect for their anonymity, their right or willingness to participate which was shown by giving consent, and beneficence ensured that the participant would not be harmed in any way. As the participants in this study are adults and living in different provinces, their anonymity was guaranteed in that they would never be able to be identified, apart from the researcher knowing who they were. The researcher in showing respect to the participants, provided a trustworthy environment where participants felt comfortable, consideration was shown for the participants' time and personal lives, and it was important that the researcher's conduct with the participants was ethical and appropriate at all times (Lichtman, 2014).

It was imperative that good research ethics was followed during interviews where the researcher kept the interview within the boundaries of the study, used the interview guide for the questions, stayed within the specified time, was respectful, courteous as well as a good listener and not a frequent speaker (Creswell & Poth, 2018). Data collection boundaries were observed and not overstepped by the researcher, who was always mindful of the feelings of the participants and not demanding responses (Patton, 2015). Responses given by the participant were not evaluated or judged and the researcher was aware that questions asked should not upset the participants (Johnson, 2017). Therefore, the conversation and words were carefully selected, to ensure that no harm was caused to the research participants or to cause their unhappiness Yin (2011).

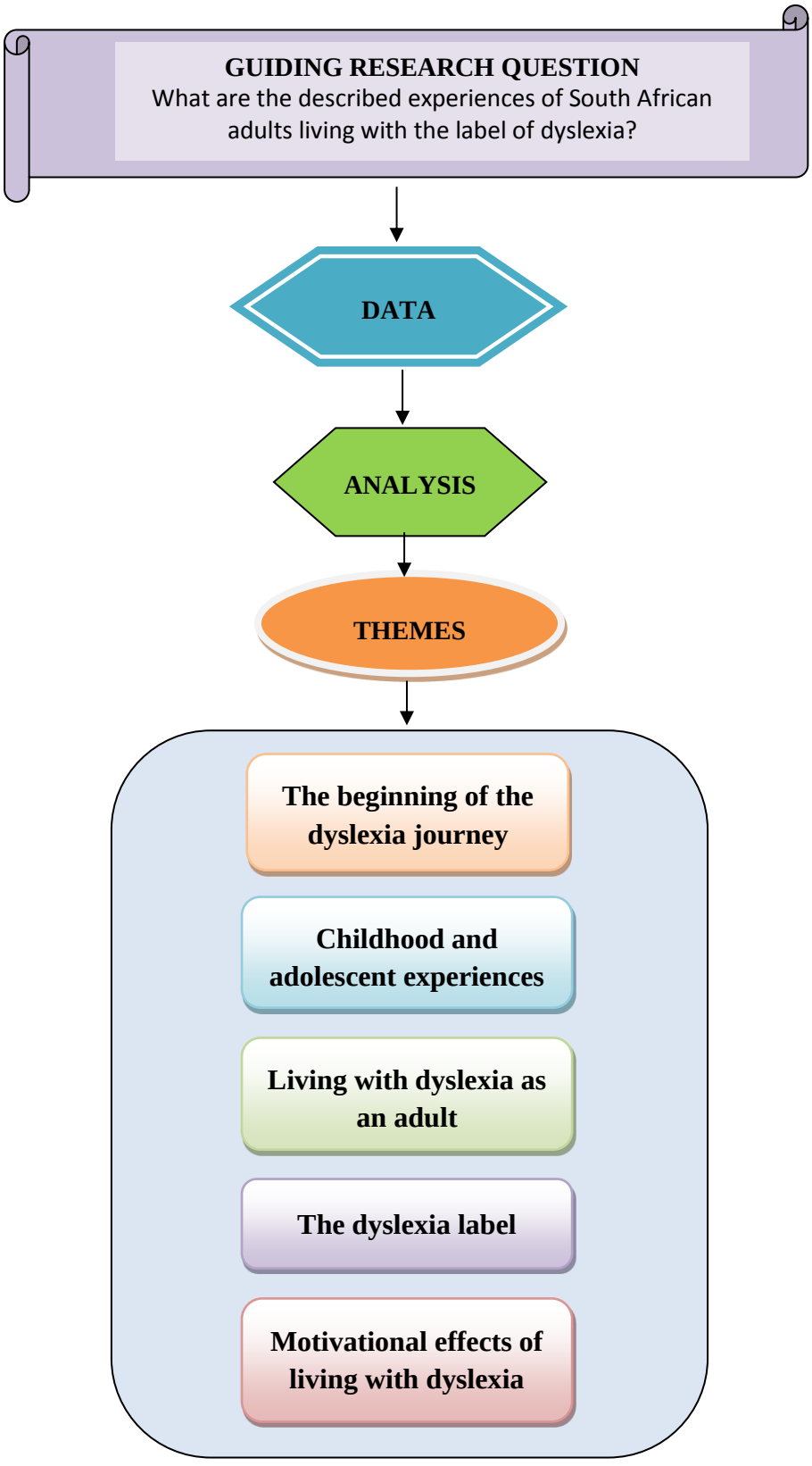
4.10 CONCLUSION

The focus of this chapter was directed at a detailed discussion and explanation of the research method and research design selected, that would enable the aims of the study to be achieved and provide answers for the research questions. Special focus was placed on the sampling procedure followed, data collection strategies and the value of the researcher's reflective journal. The process of data analysis was described in detail, including all the factors followed to ensure the trustworthiness of the research findings. Careful attention was paid to ensuring that the necessary ethical considerations indicated by this study were achieved. In the next chapter, attention is placed on the analysis and interpretation of the data collected for this study from the interviews and the researcher's journal.

CHAPTER 5

DATA ANALYSIS, INTERPRETATION AND DISCUSSION

OVERVIEW OF THE CHAPTER



5.1 INTRODUCTION

Chapter 5 gives insight into the participant's expressed experiences of living with dyslexia, the ecosystems involved in these experiences and the resultant impact of these experiences on their needs. Using Husserl's transcendental phenomenology to provide a description of the dyslexia meanings and experiences shared by the participants (Creswell & Poth, 2018), an in-depth exploration is provided by way of a detailed discussion and analysis. Themes that are influenced by the selected frameworks of the study are formed with the aim of answering the research question asked in this study. Ensuring an open mind, data analysis, findings and reflection have enabled the use of direct quotes, verification of the findings, and continuous focus directed to the meaning of the stories and words obtained from data collected (Patton, 2015).

Throughout the interviews and data analysis process, all assumptions and preconceived ideas held prior to conducting the interviews were noted in the researcher's reflective journal. This ensured that biases resulting from past personal knowledge and theoretical knowledge obtained from the literature were noted and focus was placed solely on the described experiences (Giorgi, 2008; Wertz 2005). As the aim of phenomenology is to report on the essence, which is the common experiences of the participants, the steps outlined in Creswell (2016) and depicted in Figure 4.1, were followed:

- Significant statements in the transcripts were identified;
- Meaning units from these were developed;
- Descriptions of the individuals' experiences are provided; and
- The context of these experiences is given.

These steps enabled the essence of the participants' experiences and the resultant themes to be deduced.

The research findings are grouped into five themes with sub-themes found in each. The first four themes are located in Bronfenbrenner's Ecological Systems Theory, Figure 3.1, this being the first theoretical framework of this study. Therefore, the participants' experiences within their ecosystems and based on their dyslexia are discussed. These experiences will commence with the participant placed in the microsystem and extend to their experiences of their macrosystem. The fifth theme is located in Maslow's Hierarchy of Needs, Figure 3.2, which is the second theoretical framework of this study. This theme describes the effects that dyslexia

has on the motivation of the participants. All five themes, shown in Figure 5.1, are therefore encompassed in the conceptual framework of this study found in Figure 3.3

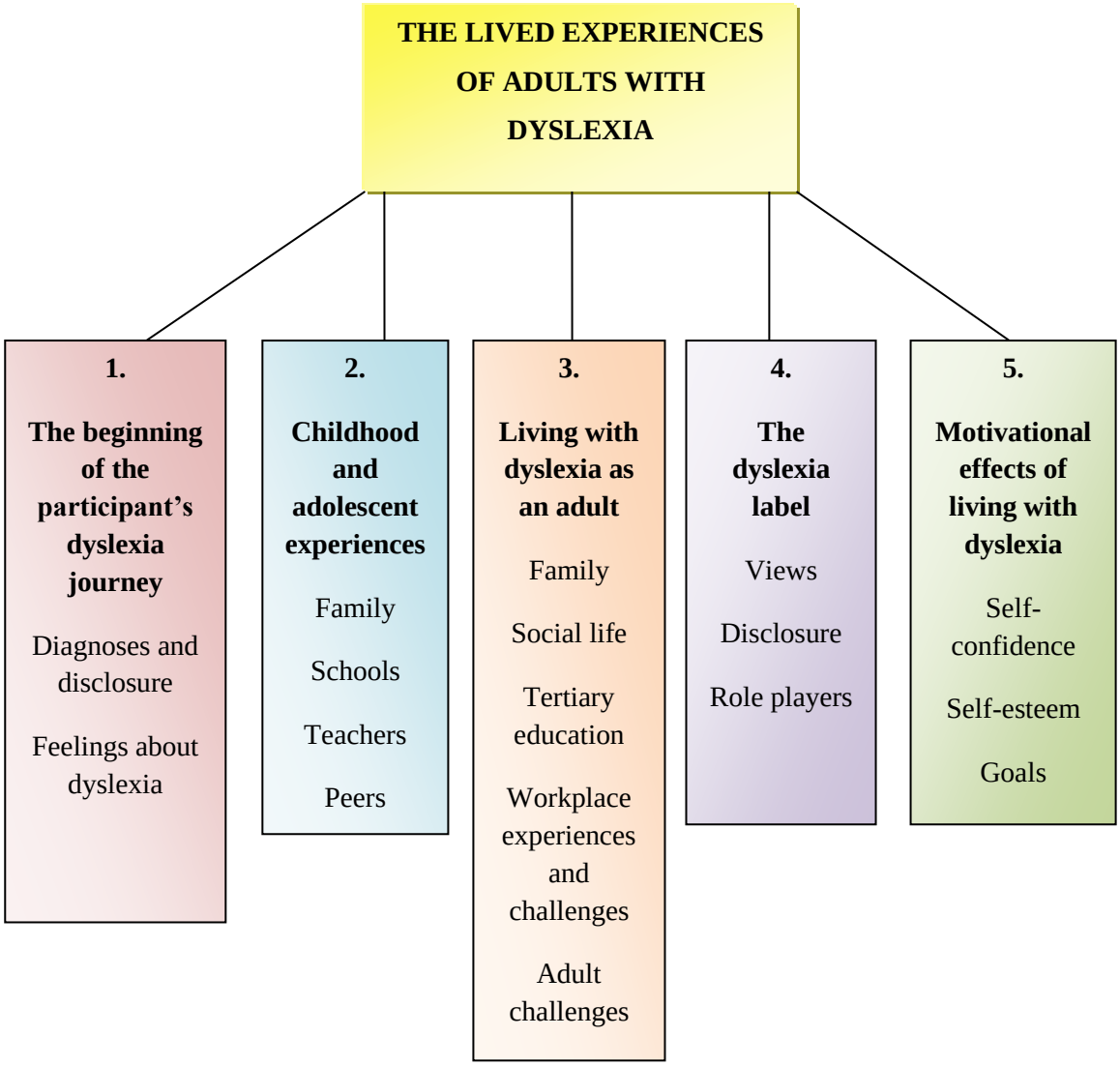


Figure 5.1: Research themes

Each theme in this chapter is discussed in two steps namely, the introduction of the theme, followed by a presentation of the sub-themes in which the participants' voices are used. Verbatim accounts are indicated by phrases or sentences in italics, which ensures that the personal meaning that each participant had attributed to the phenomenon is presented. Using the voice of the participants, and hence their actual words, forms an essential part of this chapter, and assists in negating any bias that the researcher might have.

5.2 THEME ONE – THE BEGINNING OF THE PARTICIPANTS' DYSLEXIA JOURNEY

This theme discusses the start of the participants' dyslexia journey. The focal point of this theme and hence all sub-themes herein is the participant, located in the microsystem of Bronfenbrenner's ecological systems. Included in this system are those who are closest to the participant, for example parents, siblings and possibly caregivers (Bronfenbrenner, 1979). Focus is directed to the participants' awareness of their dyslexia challenges, diagnostic experiences, knowing their diagnoses and their sentiments about living with dyslexia. In analysing these experiences, two sub-themes are identified namely:

- Diagnoses and disclosure; and
- Feelings about dyslexia.

5.2.1 Diagnoses and disclosure

Whilst a diagnosis is representative of the medical model, which views dyslexia as a deficiency, and therefore as something that is wrong with the individual, all efforts in this study to create complete distance from this model are futile. A valid diagnosis is important in this study as means to ensure that the experiences explored accurately belong to persons who are dyslexic. Where and how diagnoses occurred is varied for the participants, as indicated in Table 5.1. Two revealed that they were diagnosed by a psychologist whilst at school, with their parents playing no role in seeking the diagnoses or having to pay for it. As a result of the time lapse, these participants were unable to provide specifics about the psychologists who made the diagnoses. Five participants were diagnosed privately as a result of persistent parental efforts made to obtain diagnoses. Therefore, the costs incurred were met by the parents. One participant was formally diagnosed as an adult, but he indicated that whilst he was assessed at school, a diagnosis, if made, was not revealed to his parents.

Table: 5.1: Participants' diagnoses and disclosure

School Diagnosis	Private Diagnosis as a Learner	Private Diagnosis as an Adult	Age at Diagnosis	Disclosure of Diagnosis to Participant
Kim			11	No immediate disclosure
Walter			10	No immediate disclosure
	Stacey		7	Immediate disclosure by both parents
	Jane		16	Immediate disclosure by mother
	Mary		9	Immediate disclosure by mother
	Shana		8	Immediate disclosure by educational psychologist
	Henry		11	Immediate disclosure by mother
		Clive	22	N/A

Whilst precise memories surrounding the exact age of their diagnoses were sometimes a challenge for the older participants because of the time lapse, circumstances and memories surrounding their diagnoses are etched in their memories.

5.2.1.1 Dyslexia diagnosed by professionals sought by the school

Kim and Walter were the only participants who were diagnosed by professionals sought by the school to carry out the diagnoses. Kim's diagnosis occurred when she was a learner in a small newly established independent school, and Walter was diagnosed whilst attending a well-resourced mainstream school. The resultant intervention that followed for both participants was their placement in a remedial school for two years, described in 2.2.2. Walters's placement was decided on by the school, whilst Kim's attendance at the remedial school was the result of her mother's insistence that she should be placed there. Her mother believed that she would receive the necessary intervention that would assist her with her challenges. Whilst Kim returned to mainstream education, where she remained until Grade 12, Walter was placed in a special school that focused on vocational subjects as discussed in 2.2.2. At the end of Grade 10, this being the final year at this school, Walter was issued with a certificate; however, he was unable to recall the name of the certificate.

Both Kim and Walter indicated that their diagnoses were not revealed to them and that it was only years later that their diagnoses were disclosed. Kim clearly remembers being assessed and the person who did the assessment.

I was diagnosed at school when I was in Grade 5. My mom hid it from me. She didn't want me to use it as an excuse. When questioned about whether her mother had made the right decision to conceal her diagnosis, Kim indicated that she did not think that her mother should have done this.

> *I would have taken it a lot better. I mean if I think about my brother. If you tell him something like that he's going to take it very badly. It would have destroyed his drive to try completely* (two of her brothers were also diagnosed with dyslexia).

Walter's mother also concealed his diagnosis; however, he is very accepting of his diagnosis being hidden from him and has never questioned this decision.

> *I was diagnosed round about Grade 4. I was too young at the time for them to tell me well you got this... and for me to understand what it was. When I returned to the 'normal' classes, I think I was still struggling a bit and they suggested a technical school.*

Concealment of their diagnoses is revealed as causing much confusion, as both participants, even though they were aware of being assessed, could not understand why they were experiencing their challenges. This confusion and lack of understanding led to feelings of intense frustration.

5.2.1.2 Diagnosed privately with the school playing a minor role

A diagnosis, where the school played no role in seeking or suggesting that a diagnosis be obtained, occurred for two of the participants, namely Shana and Jane. Both sets of parents sought the diagnosis because of continually being informed by the school that their child was not coping, teachers repeatedly criticising the child's efforts and abilities, as well as the parents wanting to know the reason for their child's challenges and inabilities. It was revealed that at no stage did the school or teachers suggest that the learner's inabilities could be the result of a learning challenge. The inabilities were viewed as laziness or as the learner not trying and hence applying themselves to their work. Shana was diagnosed in primary school whilst attending a public school (2.2.2) and Jane in high school, whilst a learner at an independent school.

Shana's diagnosis occurred in Grade 3, around the age of seven or eight, as a result of the continued negativity and criticism endured from the school and the teachers.

> *My parents sent me to a whole range of different places to be diagnosed. What was going on because I couldn't read and write? So, in Standard 1 they discovered that I was dyslexic. My eyes were tested. I had a whole bunch of different tests done. I went to an educational psychologist and did lots of tests before they discovered that I was actually dyslexic.*

After Shana was diagnosed, the educational psychologist who made the diagnosis explained dyslexia to her.

> *He explained it really nice and told me that I should never feel that I have a disability of any kind and that I should remember some people are good at some things and others are better at others. So although my reading and writing skills weren't so great, he said that I will discover something that I'll be much better at than others and I should focus on that and not on the dyslexia.*

Jane's diagnosis only came at the age of 16 whilst she was in high school. She attended a mainstream school till Grade 5 and then went to an independent school (described in 2.2.2) until Grade 11, which was when she was finally diagnosed. Throughout her schooling tenure, her parents took her to various professionals seeking a diagnosis. A diagnosis was therefore a costly process for her parents.

> *My mom always knew processing was very challenging for me. I got sent to an OT* [Occupational Therapist]. *A lot of my teachers would complain to my mom that's why I went to OT but I didn't need OT. I went to a few and only the one lady said to my mom I don't actually need it. I didn't have something wrong with me in the way that I needed OT. But the thing is throughout all my years, my mom did send me to people but no one picked it up. They always thought there's definitely some sort of processing problem. I even went to a speech therapist because I didn't really... couldn't.... do the spelling. I went to an educational psychologist lady and then I went to a lady in Grade 11 and she picked it up.*

Jane's diagnosis was disclosed to her mother by the educational psychologist. Her mother also faced the dilemma of whether she should reveal the diagnosis to her, and made the decision to disclose it to Jane.

She said she wasn't sure if she should tell me or not because if she told me then I become like this is what I am. I'm identified as being dyslexic so she didn't want to have that sort of negative effect and I'm identified as that. But then she thought if she tells me then I'll be more understanding and not so harsh on myself with work.

A role was played by the school in the diagnoses of both Henry and Stacey, where the school indicated that they (Henry and Stacey) could possibly have a learning challenge. The school further provided the names of possible persons who could make the diagnosis. Stacey was tested and diagnosed towards the end of Grade 1 at the age of 7, whilst she was a learner at an independent school. Her memories of her diagnosis are vague, but she recalls battling to read and write and having to often spend her lunch breaks in the class trying to complete her written work. However, she clearly recalls the explanation of her diagnosis being provided to her by both parents.

I was never told that something was wrong. My parents explained dyslexia to me and I was told that I would need extra help with my work to get me to read and write better.

Henry attended a small independent school from Grade 1 till the end of Grade 12.

I couldn't read or write until I was 11. So obviously from like Grade 2 or 3 they would have known there was an issue, and then the actual dyslexia diagnosis I think I got around the age of 10.

In his recollections of what he endured prior to being diagnosed with dyslexia, he expresses extreme frustration.

Educational psychologists were extreme frustration to me because you know you get taken out of class with whatever I was doing and then they try and help you with all these things that are ***difficult*** [emphasised] *to do, to try and help you.*

Henry was the only participant who emphasised his experiences leading up to diagnosis and what he felt about this process.

Like I said I couldn't read or write. So, you go to an educational psychologist and they try and teach you the alphabet you know, but it's because you can't read or write. They say ok maybe it's an IQ problem. So first they do it like ... ok draw a massive 'A' and it's like I know what an A is. I just can't put I ... and then you get frustrated. Then the next educational psychologist thinks ok... no maybe it's an attention ... Well I also have ADD.

So, I got the hypo not hyper, so I can sit still but my brain's working. So, they try and help you focus on sitting still and I'm fine with sitting still. Literally making me sit still and that didn't help me.

He was of the firm view that he benefitted from the eventual dyslexia diagnosis as it put a halt to the incorrect intervention/s to which he was being subjected. The diagnosis was a great relief for him.

And then when it gets to the correct diagnosis that's the biggest thing. Then I didn't have to deal with people trying to correct an incorrect problem. That helped because then I didn't have to do the pointless stuff anymore.

Henry eloquently criticised the professionals who tried to assist him.

Because there wasn't a specific diagnosis when I was young, they were trying to fix the problems... but with a large paint brush rather than a fine one and that stuff wasn't helping me. So it literally was just like its frustrating sitting there and doing something that isn't helping. That's difficult. They just make you do whatever it was to try and help. It's the incorrect for an incorrect diagnosis. You know they're trying to help you and its just stuff that's really hard for you, and it's not helping. So, it's just super super frustrating that... when I got the dyslexia diagnosis and then they helped me with dyslexia and I didn't have to deal with that anymore. That was nice (said with smile and interpreted by the researcher as conveying happiness and relief).

At the age of 11, after receiving his diagnosis, Henry's parents sought the assistance of a private dyslexia centre where he was taught how to read and write. Therefore, apart from a diagnosis providing the answers for his challenges, its value was found in him successfully learning the skill of reading and writing.

Circumstances surrounding Mary's diagnosis were completely different to that of the other participants. Apart from Mary being educated in a home-schooling system (2.2.2), she was fortunate to have four older siblings who had all been diagnosed with dyslexia. As a result of the knowledge that her parents had gained from her older siblings' diagnoses, they were fully prepared for Mary's possible diagnosis. They knew exactly who could provide the diagnosis, with it occurring when she was nine years old. From Mary's descriptions, her family's experiences of obtaining her diagnosis appear to be the least frustrating when compared to the

other participants in this study. After diagnosis, Mary's mother explained dyslexia and her diagnosis to her.

> *My mom did and it* [explanation] *did help. And I think also knowing it from a young age, it didn't really bother me at the time but yes...I think throughout the years.....you know with the dyslexic challenges.... it did help.*

From the above, it is evident that for four of the participants, experiencing diagnosis together with disclosure, relief was experienced as answers for the challenges faced were provided. In the case of Mary, who was surrounded by successful siblings with dyslexia, diagnosis appeared to be a strong possibility and therefore anticipated. Hence she did not experience relief as the other four participants did.

5.2.1.3 Diagnosed as an adult

Clive was assessed at school after which he was moved from mainstream education to a remedial school, for two years and after which he returned to mainstream education. His diagnosis or the outcomes of his assessment were never revealed to him, therefore he sought his own diagnosis in his mid-20s to gain an understanding of himself and his challenges.

> *But prior to that when I was in Grade 3, my teacher saw that I wasn't able to read properly and I went for assessments. I then did two years at a remedial school and then went back into mainstream.*

From the above, it is evident that diagnosis and disclosure occurred differently for the participants. With a diagnosis that occurred as a result of the school seeking the diagnosis, the parents made the decision to conceal the diagnosis from their children. (With a lapse of almost 20 years since diagnosis, parents are unable to remember the names and type of the psychologist who made the diagnosis). All participants who were diagnosed outside of the school had their diagnoses revealed to them, together with an explanation of what dyslexia is. This sub-theme focused on diagnosis and disclosure and was viewed as essential for providing the background to understanding when and how each participant's identified dyslexia journey began. It also provides a backdrop against which the participants' experiences in the second sub-theme on the participants' feelings about their dyslexia is framed and can be understood.

5.2.2 Feelings about dyslexia

The participants' feelings about diagnosis and living with dyslexia were expressed with much emotion. Whilst some were diagnosed at a young age, resulting in memories of their feelings when diagnosed being vague, they were able to eloquently describe their feelings and experiences.

5.2.2.1 Prior to discovering

As revealed, diagnosis and discovery did not occur simultaneously for all. Participants, whose diagnoses were not disclosed to them, went through school never understanding why they were experiencing their learning challenges. This led to feelings of confusion, frustration, self doubt and hopelessness. These feelings were aptly recounted despite the passage of time. Their facial expressions matched their revealed feelings and the words selected in their descriptions and answers.

Both Kim and Walters's parents chose not to disclose their diagnoses to them, which led to them being confused and questioning their academic abilities. The impact of Kim's confusion is revealed as negatively affecting her, even as an adult. Kim clearly remembers her confusion with her challenges and her difficulty in articulating them.

> *Basically, what happened was I realised that I was struggling to read. I tried to explain to someone that it was difficult and they told me I just need to practise. So I tried to practise but it just got frustrating. The word 'the' and 'bee'. I couldn't figure out how to put the sounds for 't... h... e'....' together and I couldn't figure out why the 'b' looked like 'd' and the word didn't make any sense. This is weird. It made me feel like there was something wrong with me, like I was a bad student. I didn't know what was going on and I didn't know how to articulate to somebody that there was a problem. That something was happening and I didn't know how to deal with it. It made me feel like I was the outside student and it frustrated me because I was like I am good.... why am I not performing? The learning part was not the problem ... the problem was the difficulty with reading.*

Walter was very brief in his description of his feelings prior to knowing.

> [I experienced] *feelings of confusion. Am I different? Why is everybody else going through it fine and I'm struggling? I know I was confused with what was going on and I didn't understand it.*

Jane's frustration and confusion, on the other hand, was caused by the failure of numerous professionals to diagnose her dyslexia, resulting in her late diagnosis. She was diagnosed in Grade 11, therefore over 90% of her schooling had occurred with her never knowing or understanding why she was struggling academically, unlike many others in her classes. The emotional pain experienced was evident in her entire demeanour and the careful selection of her words: *I just kept thinking ooooh I'm just stupid.*

As revealed by Kim and Walter, non-disclosure impacted negatively on them and caused self-doubt. Whilst for Jane, a late diagnosis resulted in her experiencing the same, thus validating the importance of an early diagnosis.

5.2.2.2 Reactions to discovering and the explanation

All participants reacted positively to discovering that they were dyslexic, and at no stage indicated that they asked the questions "Why me?" Diagnosis and disclosure of the diagnosis to the participants occurred almost simultaneously for Henry, Mary, Jane and Stacey with their mothers disclosing and explaining their dyslexia to them, immediately after the diagnoses were made. Shana was informed about her dyslexia by the educational psychologist who diagnosed her. All five participants stated that the diagnosis and disclosure assisted them to not only accept their learning challenge, but also themselves.

Stacey was of the view that as a result of her being diagnosed at the age of 7, she was too young to feel anything negative. Henry's diagnosis and discovery did not have any impact on him because his literacy challenges have never affected him in any way. He had never viewed it as being a problem because he knew and knows that he is very smart. However, diagnosis, despite his feelings towards his challenges, ended his frustration caused by all the attempts made to assist him. A diagnosis was therefore extremely beneficial for him: *That [diagnosis] helped because then I didn't have to do the pointless stuff anymore. That's when I started reading and writing at the age of 11.* After diagnosis, his parents enrolled him at a dyslexia association where he was taught how to read and write.

A full explanation of dyslexia was given to Jane by the director of the local dyslexia association whom her mother had contacted. Jane viewed this person as someone that she could identify with and who encouraged her. Her emotions indicated relief, joy, reassurance and comfort in having someone that understood her challenges.

She really explained it to me. It's just nice talking to her because she's just soo understanding about everything because she also has dyslexia. So, it's just nice to have someone who can completely and utterly understand.

Even though Shana was young when she was diagnosed, the positive explanation provided by the educational psychologist who diagnosed her, was imprinted in her memory. This explanation was and is her driving force to always view herself positively.

He explained it really nice and told me that I should never feel that I have a disability of any kind. That some people are good at some things and others are better at others. So although my reading and writing skills weren't so great, he said that I will discover something that I'll be much better at than others and I should focus on that and not on the dyslexia. So I never really felt bad about it at all, frustrated yes.

Mary's discovery and the explanation provided were similar to Shana's; however, having older siblings who have achieved despite them having dyslexia, assisted her acceptance and resulted in her positivity: *My mom explained it a lot to me and it did help.*

Eventual discovery for Clive, Kim and Walter provided answers to their many unanswered questions. Clive carefully thought of the correct words to use regarding his reactions to eventually discovering that his challenges had a name.

Ease. I don't know if that's the right word but it makes it easier. It definitely makes it easier. I don't think why me because I know why me. My dad's got it [discovered after Clive's diagnosis]. *I don't know but it does make it easier when you can just try and explain to people. I don't have to beat around the bush. You don't have to go into massive detail. This is the issue. This is how I need help to deal with life...*

Walter also pondered my question about discovering that he had dyslexia and the effect of the discovery. He thought and then carefully selected the words to describe it. His discovery occurred when he was out of school, as a result of his mother not revealing it to him whilst he was at school.

I think that I had a sense of relief, because at least I knew what it was, and what I was doing wasn't my fault. It was more just a sense of relief. So now I understood what it was.

Kim's mother finally revealed her diagnosis to her after seeing the frustration that she was experiencing in high school and her inability to complete her exams on time.

> *Then she explained ... well you're dyslexic so you read slowly and I said well that makes sense. I couldn't even spell the word* [dyslexia]*. It's a horrible word for someone who can't spell. So, I sort of wrote it off as well. I just won't tell anybody about this. I almost feel like in some ways my mom did me a favour by not telling me at a young age.*

Data revealed that disclosure is of vital importance as it not only provides answers for the challenges faced, but also assists in acceptance of the challenges and increases the determination to succeed.

5.2.2.3 What dyslexia means to me

Most of the participants embraced their dyslexia positively and saw it as a driving force to becoming the people that they are. Walter indicated that he was aware that there are degrees of difficulty associated with dyslexia and was of the view that his challenges were not as great as others with dyslexia: *My case wasn't as severe as some of the cases that I've read ... mine was minor.* His dyslexia therefore meant that: *I always felt like that people didn't think I'd be able to do something. So I worked harder at it to prove them wrong*

The explanation provided to Shana about her dyslexia impacted positively on her views of her dyslexia.

> *I never really felt bad about it at all. Frustrated yes, but the more I take power of it the better it's always for me. I've always felt like I've got a little bit more to prove than others do.*

Henry's feeling towards what dyslexia meant to him and the impact that dyslexia has on him, was consistent throughout the interview.

> *It just gives you a thick skin. It's not particularly a negative thing; it's not a bad thing. Tell me one thing that's bad about dyslexia. You struggle with reading and writing. This is not the worst thing in the world. I've always been a smart kid and that other people didn't see that I was smart, it didn't bug me that much. So, I have dyslexia, but I got a degree in ... If someone mocks dyslexia, well it means I'm smarter than most people. I just can't read or write. Everything in life has balance you know and good comes with bad, bad comes with good.*

Despite the emotional pain shown by Jane throughout the interview, it was evident that she had embraced her dyslexia: *It is my unique ... like it is part of me ... it's part of who I am.*

Kim's feelings towards her dyslexia could be based on her diagnosis not being disclosed to her and therefore never understanding her challenges. Her feelings towards the word 'dyslexia' were indicated using almost the same words in an audio WhatsApp message.

> *It's sort of funny because the reason why I don't like the word dyslexia is because I can't spell it. I can't figure out how they go together. It is a horrible word. It's a complicated word for somebody that's ... How much more of an insult do you need? Like you're going to give me a name for the thing that I have that I can't spell because of the thing I have. It's just funny. I don't even know* [that] *reading disability would be something more acceptable.*

Her lack of understanding affected the way in which she viewed herself.

> *I always felt like my screen was cracked. You know like your cell phone still works but the screen is cracked. Broken but it's not unfixable. That's the best way I can say that.*

She however, acknowledged that her feelings had changed with her acceptance.

> *It's okay. I'm dyslexic because I battle when I read. I'm okay with it because it's not hurting anyone. I'm not hurting myself. I don't think there's a cure for dyslexia. I don't think there's any way to really rectify it. You can just learn how to crutch better. I feel like I'm tooting my horn when I say that dyslexic people are abnormally smart. I know I'm clever. I know because I've succeeded in everything that I've ever tried to do, but I think my mom has a lot to do with that. Yeah, I understand things very quickly. I know what's going to happen very fast. I can figure stuff out.*

Mary showed maturity towards her feelings about her dyslexia.

> *I think there's so many upsides to dyslexia and you just have to focus on them and to find a way to make it work. If you believe that you have a problem then you will have a problem. Whereas if you believe that you have dyslexia and there's upsides to it, you'll have dyslexia, but you will have upsides to it. It's that basic. It's strength, but it does come with challenges.*

Clive appeared nonchalant towards his dyslexia and this was verified with lots of laughter throughout the interview.

> *It's just an aspect. I've got dyslexia. That's it. It doesn't really affect me. Obviously if I didn't have it, it would make a lot of things easier and I might have excelled and done a hell of a lot better in life and did other things or maybe become an engineer.*

The emotion shown when stating this was one of fact and not one of regret.

Whilst Stacey showed acceptance towards her dyslexia, it was evident that dyslexia was her driving force.

> *The only struggle I've had was accepting I'm not 'normal' and the hard part is that I feel I can overcome the issue on my own. If I work harder, I'll get better. If I read more I'll understand. But overall, I always feel like it can easily be an excuse for not doing something and I really don't want that. I want to be able to do a task the same as everyone else.*

Participants were asked the question: "If you had the choice to live with or without dyslexia what would you chose?" The responses were varied with some having to ponder the question while others answered immediately.

Shana: *Yes I would like to have not had it and have a normal life where things are easier. I really actually wanted to study and become a doctor. So it's always held me back.....the fact that I've never done my matric. But then you know there's pros and cons. I don't think I'll be the person I am today if I didn't have to have the challenges that I've had to face in my life. Being dyslexic isn't all that bad.*

Mary: *It never bothered me to the fact where I wish I'd never had dyslexia. I understand now what the downs are. I still accept it and it never bothered me to the fact where I wish I'd never had dyslexia. I think I would choose to have it purely because I think there's so many advantages to it. Also, without it, but I think I chose to have it because there's a purpose for everything.*

Henry: *It's a difficult question because I know what to expect with the dyslexia and I don't know what to expect with not having it. I would have probably gone through to a different high school. I would have gone into a mainstream high school. Okay so it would have been a whole different school experience. I wouldn't change my dyslexia, because it hasn't held me back that*

much. It hasn't been a huge effect on my life. It's helped me become more determined to prove people wrong.

Clive: *Definitely not, 100% no. I don't think anybody would want it. It will make things a lot easier and not having .....not that I've ever worried about it, but people thinking that you are an idiot or that you are stupid again.*

Stacey: *My dyslexia has stopped me from doing things at the same pace as everyone else. As much as what I am a stronger person for having battled to achieve what I have, I do sometimes wonder if I might have accomplished more at this stage in my life. But I never want to see my dyslexia as an excuse for not having done things. Things would be easier without dyslexia. It's hard to be different. However, I have learnt to work with my challenges far more than I did as a child. So, as a child I would not want to be dyslexic, but as an adult it's ok.*

Whilst the participants were aware that living with dyslexia poses challenges with both negatives and positives, all embraced their dyslexia and revealed that it was just an aspect of them as well as a unique part of them, that increased their determination to succeed

5.3 THEME TWO – MY CHILDHOOD AND ADOLESCENT EXPERIENCES

Four sub-themes have been identified in this theme namely, the family, schools, teachers and peers. Guided by Bronfenbrenner's Ecological systems theory that human development occurs within multiple environments or systems that interact with each other (Bronfenbrenner, 1994), the participants' childhood and adolescent experiences of living with dyslexia within their surrounding systems are discussed. Included in the discussion are the effects that these experiences have had on the lives of the participants.

5.3.1 Family

Whilst all participants received support from their families, the extent of the support received differed as a result of extenuating circumstances. The focal point of support received was:

- Assistance given at home with schoolwork and homework. Whilst emotional support was also provided by the parents to the participants, their dyslexia, the challenges faced or the cause for these challenges were not broached by the parents and therefore discussed with their child.

- Assistance given at home with schoolwork and homework. Emotional support was also provided by the parents to the participants with the participants' dyslexia being spoken about freely, if the need for this discussion arose.

Even though some parents did not discuss dyslexia with the participants when they were young, all indicated that their parents always showed understanding and never frowned on their inabilities and challenges. Therefore, despite the frustrations sometimes experienced by parents because of their children's dyslexia challenges, as well as the parents' inabilities to provide the academic assistance needed, all participants were of the view that their parents showed absolute acceptance of their dyslexia challenges. This view was based on the encouragement and assistance that their parents provided to them, as well as their parents never showing any frustration towards their inabilities caused by their dyslexia challenges.

- **Support given without the parents discussing their child's dyslexia**

Whilst Kim and Walter's parents did not discuss their dyslexia with them, both sets of parents always provided support, assistance and encouragement with the school challenges. Walters's parents focused on his homework and tried their best to assist him.

> *For homework my parents would spend extra time with me to go through what I've done and if I did confuse the letters, again show me that it's wrong and tried to help me correct it.*

Kim showed absolute appreciation to her mother (single parent) for all the support. In every section of the interview, she referred to her mother (68 times in the interview) and gran (12 times). She stated that she would not have coped and achieved if it were not for this support and guidance. She clearly remembered reading to her grandmother every day whilst being driven home from school.

> *I would read to my gran in the car and I would sound out the words the way that they looked but because she couldn't see the page, she didn't realise that I wasn't actually reading real words. I was just making up a story based on the picture that I saw. So, for about two years driving in the back of the car reading to my gran I was doing my reading in their mind. Like everybody believed I was doing my reading because I was talking about a picture that I saw but I never actually read anything.*

Kim provided a lengthy clarification for the support and encouragement provided by her mother. This support and encouragement were given before and after revealing Kim's diagnosis.

- *She made the best effort to let us feel like we had every opportunity to be the best version of ourselves. I'm grateful for that ...*
- *But I also feel like it would have been a lot easier if it wasn't just my mom against the world.* (the school attributed her challenges as being caused by her mother).
- *My mom made me work harder.*
- *My mom is the reason why I didn't give up because she never let us put something down if it was difficult ... Work the problem don't just give up.*
- *I'm so grateful that I had my mom. She didn't let us give up.*
- *She never made it* [dyslexia] *feel like it was a dirty word.*
- *My mom made sure that I knew that I had to, because if you don't believe in yourself no one else is going to do it for you. You have to be your own advocate.*

Clive, on the other hand, did not experience the same support as Kim did from his parents. His dad is also dyslexic and was therefore unable to assist him with schoolwork. Whilst his mother understood and knew that he had his challenges, the time spent assisting him was limited. She focussed more on his younger brother whose dyslexia challenges were far worse than Clive's. Clive indicates this without showing that he was neglected: *N..... had the bigger issues and his issues always had to be fixed and sorted out and focused on.*

Whilst parental support is of vital importance, Kim, Walter and Clive did not criticise their parents' failure to discuss dyslexia with them. Clive was very understanding and accepting of his parent's failure or inability to provide much support to him.

- **Support given with the parents discussing their child's dyslexia**

Family support and assistance was given to five participants with their dyslexia being freely discussed, if the need for the discussion arose. Mary was constantly encouraged by all members in her family which included her older siblings, despite living with the challenges of dyslexia themselves, as well as her mother which helped her a great deal. They taught her to be positive and to embrace her dyslexia.

We are taught to accept it with an open heart. My parents are optimistic. They said it was a big advantage because we think differently. In a way, we're actually one step ahead of the other children without dyslexia, but in many ways, we are also one step behind.

Jane received immense support from her parents and in particular, her mother. Her dad has dyslexia and could not really assist her with her schoolwork. (His diagnosis was only discovered after Jane's.) Despite his inability to assist with her schoolwork, his assistance and support was provided. Her parents consulted many professionals seeking a diagnosis, and during this period they also paid tutors to assist her with her schoolwork. When she changed from a mainstream school to an independent school (discussed in 2.2.2) her mother, with the support of her dad, moved into a flat that was close to the school. Her parents made this decision so that Jane did not have to be placed in a boarding establishment, as the new school was 46 kilometres away from her home. Every weekend they travelled back to their family home. Her mother endeavoured to assist her with her schoolwork to the best of her ability.

We would do spellings for the test on Friday. So, we'd do half the spellings on Monday, the other half Tuesday and then we would do all on Wednesday. And I wouldn't remember the words so she'd be like okay and I would say this is new. So, every night we'd both end up in tears because she didn't know how to teach me and I just wasn't getting it.

It was evident that Jane's parents like many of the other participants' parents tried their best to assist their children and this caused undue stress.

Shana's family also sent her to numerous professionals to be diagnosed, as well as paid for her to attend study centres for extra tuition. She was emphatic in indicating the immense support provided by all in her family.

100% - whole time, even our domestic worker was really good with me trying to help me with my homework after school. My mom worked until I was in Grade 9 so I had a day mother who would help me with my homework every day. And days when I couldn't go to her my domestic worker or my brother or sister if they didn't have a lot of homework, or anyone that I basically knew used to... because I wasn't shy to say I needed help.

Her family assisted her with her tests and exams.

My mom or my brother or even my baby sister used to read my schoolwork to me. I'll tape it on a Dictaphone and I would play it back and that is how I would study and learn.

Henry received much support from his family, despite them having to provide such support to his younger brother who was also diagnosed with dyslexia. They would read to him from encyclopaedias and never placed any pressure on him regarding his challenges. Therefore, absolute acceptance of his challenges was always shown and they always tried their best to assist him.

Stacey was very appreciative of the assistance and encouragement that she received and still receives from her family.

> *In high school I moved cities and the teachers were not as aware or cared about me being different. I found it hard but with the help of my parents I learned how to manage it. I just know that I love my family and without them I don't think I would be able to be me.*

The majority of the parents of the participants in this study spoke freely to their children about their diagnoses of dyslexia. This could be deduced as the parents' acceptance of the diagnoses, as well as the parents knowing the importance of removing all stigma towards dyslexia in the home.

5.3.2 School support and learning experiences

Focus in this sub-theme is directed to the participants' overall learning and support experiences in the schools attended by them. With the exception of Mary, who is home schooled (currently completing her final year), all participants indicated that they were unhappy at school. Their challenges were not understood, therefore resulting in them not receiving the required intervention. Furthermore, the schools that they had attended refused to make any concessions for them. They are of the view that their schools did not motivate them to succeed. With the exception of Mary, all participants indicated that homework was a major challenge. Mary was therefore the only participant who indicated no unpleasant schooling experiences and indicated that she would never want to change her schooling system.

Despite Jane's formal diagnosis of dyslexia, her family were informed by the independent school that she attended, that no concessions would be made for her in terms of being assisted with extra time in tests and examinations. Based on this refusal to accommodate her learning

needs, her parents moved her to a home school centre [6] in Grade 11: *There were only eight of us in a class and that helped me a lot more because it was more one on one.* This type of school granted her the needed concessions. She was allowed a scribe to read the examination questions and they also gave her an extra 15 minutes in examinations and tests. Having a scribe necessitated her having to write in a private room. She however, summed up her school experiences from Grade 1 to Grade 11, which was interpreted by the researcher from the facial expressions shown as indicating dismay and despair.

> *It was all very challenging and I wouldn't say any of them were very.... like the happiest. I never really enjoyed school overall.*

Shana's family sent her to numerous mainstream schools hoping that she would find one where she would be happy. Despite the various schools being informed that she had dyslexia, scant support was provided to her.

> *I ran out of schools to go to... Some schools had suggested that I go to F ... the School for the deaf and I was... I don't understand. I'm not deaf. There was another one in Durban that was for disabilities. But I didn't want to go to any of those schools.*

Henry's parents were also advised that he should attend a LSEN school (discussed in 2.2.2), but they too, did not follow this advice. However, Kim, Clive and Walter attended remedial schools, which they criticised and indicated that it was of no value for them. Walter was of the firm view that he would have gained more if he was left in a mainstream school and not sent to a short-term special school. He indicated that after the two years in the remedial school he was placed in a technical school. Here a teacher told him that he should have been in a mainstream school doing non-technical subjects as he had the ability to be in a mainstream school. The system therefore held him back, placed him where he should not have been placed and prevented him from achieving his full potential.

> *They moved at a slower pace obviously to accommodate everybody that was in that class. There wasn't everybody who had dyslexia. Everybody had something different ... I'm not going to say wrong with them but.... difficulty. So, we had to move slower for other people and you just took forever to get through things. Everyone was taught the same thing.*

[6] This was a private United Kingdom-based, co-ed home-school centre that enabled their learners to write either the National Senior Certificate examinations (NSC) that are controlled by the Department of Basic Education, or the Cambridge International Examinations

Kim was the only participant who indicated that in her first two grades she regularly received corporal punishment metered out by the school principal.

> *I was in the office for a paddle or a hiding at least once a week. Once a week for two years I had a paddle every single week. At least some weeks I would have two or three paddles in the week.*

She was critical of the remedial school that she attended: [Name of school] *school had in some ways failed to remedy any of that* [her literacy challenges]. *That is what the school should have been doing, which they didn't.* When she returned to mainstream school, she felt judged and uncared for.

> *They knew I had come from* [name of school] *so they automatically assumed I was a poor learner. They just didn't know I have a reading disorder. Did I have a numeracy disorder? Was I colour-blind? They didn't know". I was told that I wasn't allowed to take motor mechanics and technical drawing because I'm a girl, and that I should rather study cooking and typing. And I was like but I can cook and type, I want to learn something I don't know how to do. They try and rein the students in to not let them go too far ahead of themselves and I don't know if it's for protection or for ego.*

Clive's selections of words used were powerful in conveying his school experiences. He indicated that he was placed in a remedial school for two years … *and then basically thrown back into mainstream*.

He was very critical of the special school that he attended.

> *They don't specialise in things. They have all the remedial people in there. But you had children that were autistic; you had children that had reading and writing issues. It's the huge variety of different learning disabilities*.

His return to mainstream was a negative experience. The high school attended by Clive was in the same area as that attended by Kim, but was a boy's only school while she attended the school for girls. They both indicated that they did not enjoy their respective schools.

> *It's a horrible school. The quality of the school is just terrible. There was no drive in that school. If you wanted to do extra subjects you had to go and pursue it yourself. If you wanted to do art or drama... these are the subject we offer and that's it. There's nothing*

more than that. So there weren't a lot of options when it came to stuff like drama. I loved drama but I wasn't able to do it. It wasn't offered.

He is also very critical of what was taught. He referred to schools as forcing him to do:

… 'stupid things'. I'm saying stupid things. But like history to me... learning about World War 3 or World War 2. According to the teachers, it's teaching you how to learn research because in order to do the subjects you have to go into a library and research it. So, I say why don't they teach you research why must they mask it under this history because a child is not going to remember all these dates and stuff like that ... but he's going to remember the skills. So why not teach the skills instead of the content. You don't learn skills at school, life skills and work skills and job skills and....

From the above, it is evident, with the exception of Henry who always believed in his intelligence, and Mary who was home-schooled, that most participants did not have happy memories of their schooling experiences.

5.3.3 Teachers

All participants felt intense disillusionment towards the majority of their teachers. Their experiences of their teachers were conveyed in a manner in which absolute hurt and despair was detected by the researcher. The hurt experienced by Jane appeared to remain with her.

A lot of my teachers would complain to my mom. They would keep complaining that I wouldn't do work or this and this and that. My teachers would keep coming to my mom saying she needs to go see someone. A lot of comments from my teachers in my reports would be like she's making progress but she just needs to try a little bit harder or she needs to focus a little bit more.

Intense anguish was shown when she said: *It's not that I'm not* (painful laugh) *it's just like it's hard...* Whilst attending an independent school, Jane' feelings were negatively affected by a person whom she referred to as the secretary lady. She however, was not sure of this person's actual position at the school because this lady was new to the school. The words of this person were mentioned more than once during the interview and appeared to have scarred her emotionally.

She called me and she wasn't very nice. She was saying if you're not going to get your marks up no one's ever gonna look at you after school, and you're not going to get into

varsity. I didn't know really how to take that. It was very harsh and I was really hurt by it because I knew I wasn't. ... There were some girls that were doing worse than me and I was just like oh it is hard and I don't understand. Why call someone and tell them that? That's not what you need to hear because it's just going to put you down. Anyway, so she said that to me and I was really hurt by it.

When asked by the researcher if she had teachers who were understanding and tried their best to assist her, she indicated that there were only two teachers who did this.

My Grade 6 teacher. I did extra Afrikaans lessons with him and he also just on his own. My mom and I both agree that he was always very comforting and supportive. Oh, and my maths teacher in Grade 8. She was also very sweet but I just had maths with her and she did not do as much as he did.

She summed up her teachers' actions as: *I don't think anyone* [teachers] *really likes to leave the box to see what's on the other side.*

Shana also referred to the lack of care shown by teachers and their deliberate actions to hurt and cause her embarrassment. The teachers' actions led to her family doing their utmost to assist her which included changing her schools attended on a regular basis.

Because I was so miserable and my parents were trying to find a school that would help me out … where I wouldn't feel like I was an idiot because I was constantly being told that I was an idiot or I was lazy. So, my parents were just trying to help me find some way where I felt like I fitted in. I did get quite a few good teachers that were quite understanding and quite helpful.

Whilst indicating that the number of learners in her classes could have contributed to this, she still felt that most of her teachers showed no compassion.

Some teachers were great, some not so good. No teacher would ever help in ever guiding me or reading it out to me and it used to really get me extremely frustrated to a point where I eventually wanted to give up. Some teachers still felt that I was lazy and not willing to participate [despite them knowing about her diagnosis], *and I guess some teachers ... some of my classes were really big and the teacher didn't have the time to focus her energy. I get that but I feel some teachers just didn't want to. They didn't care. I felt they were not helping me to the best of their abilities. I took subjects that I knew teachers were willing to go the extra mile with me. Some teachers used to be quite mean*

and pick on me. Make me read out constantly in class knowing that I had an issue. The educational psychologist at one stage wrote a letter to the school to say that I shouldn't be reading out aloud in class because I get anxiety from it and it makes me feel embarrassed. But some teachers would purposely call on me to read out and then occasionally students would laugh because sometimes just the simplest word I couldn't even say, like I'd be stuck on it.

She relived her memories of her Afrikaans teacher in Grade 6.

He was a meanie. He decided the one day to do a spot Afrikaans test and Afrikaans was my nemesis because I battled with English and now, I was doing a second language. It was very, very difficult for me. He was in a very foul mood; walked into the class one day and told us we were writing an exam. We had a double period. He said the first period we would write the exam and the second period he would mark it. Anyone who failed was going to get six of the best. So, I immediately started to panic. I did so bad I even spelt my name and the date wrong. So, I got minus marks and in front of the whole class he belittled me and told me I would meet him in the office for six of the best at break time, which was supposed to be the next period. I then excused myself from the class to go to the bathroom but went downstairs and called my mother and got my mom to come to the school and rescue me.

Shana however, paid tribute to her English teacher who understood and supported her and with whom she still keeps in contact. Of the many teachers encountered during her schooling, the actions and attitude of this teacher live with her.

He went over and above for me every step of the way. Everything was on higher grade which made it even more of a challenge for me. But he was extremely amazing. I would write extremely untidily so the teacher couldn't pickup if I'd made a spelling mistake or not and he never complained to me about my handwriting. As long as I had written something down, he was satisfied and happy. He would always make sure that he would take time out in the class and then get me to read it to him. He knew I was never actually reading it from the paper but from knowing what I'd written and then always mark me just on that. Like spelling never counted with him. He just ignored my bad spelling, my terrible handwriting and he was always so amazing. If ever we had to write an exam or write a test, he would always stand right next to me and ask if I'm okay and if I needed any help with anything, if he needed to read anything out. He was an amazing teacher.

Clive often referred to the failure of teachers to understand his challenges, assist him, as well as the lack of care shown by them.

> *I couldn't tell my teacher listen I've got learning issues. They were just kind of go, well that's your problem. You know come with the class kind of thing... go move with everybody as if you were all sheep and you had to kind of go into the same level and it didn't matter. Everybody's different. But they want everybody to go through the same way. You stand up on the board you got to learn this you got to read this you got to be able to get to this level before you can get to the next grade kind of thing. There's no like different people learn differently and dyslexic people need to learn how to learn different.*

Clive's adult views of his teachers were harsh, and his school experiences remained entrenched in him.

> *The teachers are there just to get their salary. At the end of the day a lot of times a lot of them you can see they kind of almost given up with life. There was no push or extraness or there was no kind of drive in that school. I never tried to excel. I was able to.... this is a problem that I had. I wasn't stupid and I knew I wasn't stupid.*

A teacher's lack of understanding of his challenges was highlighted in the following experience:

> *I remember doing one of these aptitude tests where you've got to look at how square boxes do this and how to unfolded them, and these things. My teacher actually came to me and this was in Grade 8. Well it was in high school and she said to me you have got a serious issue in that you need to pull your finger out of your a...* [Profanity] *and do some work because according to your test you are highly intelligent, but this is what you producing. And I just went mmmm ja … that's how things go kind of thing. I knew I was able to do the more intelligent things. I just did … I remember her literal words were you going to pull your finger out of it, because according to your test results you should be doing a hell of a lot better. I was coming last in class.*

Kim's school experiences and the support provided to her at an all girl's high school was similar to that of Clive's experiences at an all boy's high school. Failure shown by most teachers to assist her, understand her challenges and to care were her dominant experiences. She indicated that she was in trouble all the time and that the teachers felt that if she practised her reading,

she would not struggle. Like Clive's teachers, Kim's teachers showed no understanding of the challenges faced by those with dyslexia.

Walter indicated that he noticed that his teachers in the lower grades would get frustrated with his academic inabilities. However, in the technical school as he progressed into the higher grades the teachers displayed more understanding. Stacey whilst not recounting negative or positive teacher experiences was of the firm view that her teachers did not understand her challenges and that they were very uncaring to her *being different*.

The failure of teachers to understand their challenges, to comprehend the efforts of the participants in this study and to show care was disclosed in all interviews with the exception of Mary, who was home schooled (currently completing her matric certificate when the interview took place). However, some participants were able to reflect on a very small number of teachers who did show care.

5.3.3.1 Feelings experienced as a result of teachers' actions and words

Despite the passage of time that has occurred since being a learner, the feelings experienced by all participants as a result of their teachers' actions and words, indicated that they still carried the scars from these words and actions.

Jane: *I didn't need any sympathy or anything. I just needed understanding and just like support from them and they didn't really show that at all. I actually do have a bit of a problem that I'm not using it as a crutch but I just want you to know like you can't... you can't have horrible comments to say to someone who's actually genuinely struggling... struggling with something. It's not nice even if you are just a little bit slower than everyone else it doesn't matter. Just go at your own pace* (smirks.) *Like why does everyone have to comment kind of thing...?*

Shana: *I was quite frustrated because a lot of the time the teachers would tell me that I was lazy because I didn't want to read and write. So, they would say that I was lazy and it used to frustrate me because I wanted to read and write. I just... I couldn't. Physically I could do it and it used to be very frustrating because I'd be interested to see and to do the work in class because I could sit and listen enough to remember everything. But then when we had to sit and read and write it ourselves, I found great difficulty and that's it. It really used to frustrate me.*

Henry appeared to be impartial to his teachers; however, he often referred to the bad treatment metered out by the school to his brother. Feelings of anger and outrage are expressed. Stacey's feelings based on the teachers' words and actions made her questions herself: *I always felt like I was working hard but my reports always said I was lazy and didn't work to my full potential. So maybe I didn't … I don't know honestly.*

Clive revealed that the teachers' attitudes and actions led to him giving up.

> *I had hopelessness at times where I was kind of ... I can't really show my full potential because I can't show it in this way. I need other ways to be taught. I knew I had potential.... I wasn't stupid. I'm still not stupid I don't think but because it was you had to show your potential like this, through literacy through numbers. I just got to a point where I just didn't care. I'd literally ... I'd tear my files in about three pieces of paper. It got to a point where I didn't want to be there anymore so I chose not to even partake. That's why I failed matric.*

Kim's revelation of her teacher experiences indicated the trauma that she experienced as a learner.

> *They made me feel like there was something wrong with me like I was a bad student. I was constantly being told I was a bad student because I was in the office at least once a week for a paddle. I had detention pretty much every single break. I didn't know how to articulate to somebody that there was a problem ... that something was happening and I didn't know how to deal with it. It makes me feel like I was the outside student. I got disciplined at school for being a poor reader right up to the point where ...* [an educational psychologist's name] *was like she's not reading badly because she doesn't want to try.* ***How could they think that?*** (Kim stated this with her facial expression revealing the conflicting emotions of astonishment, despair, hurt and disbelief at the memory).

Participants revealed that the importance of teachers understanding that all learners are different, and not passing judgement on those who are different, is of vital importance for the well-being of learners. Teachers' words and actions, whether positive or negative, remain with the learners for their entire lives.

5.3.4 Peers

From the responses given, the participants' personality appeared to play a significant role in peer interactions and experiences. Walter, Henry and Mary were very brief in relating their peer experiences. Walter appeared almost stoic in his peer experiences when indicating that he was unaffected by his peers' reactions to his dyslexia. However, he repeatedly referred to people's reactions and judgements of his adult life choices. Henry, who firmly believed in his intelligence, indicated that his dyslexia played no role in the way in which his peers interacted with him. This could also be influenced by having attended a small independent school where more care was shown to him as a result of having fewer learners in a class. His classmates knew about his dyslexia and he revealed that he was never teased. Mary indicated that despite having been teased about her reading and told by her peers that she should be able to read at her age, it did not bother her.

Clive light-heartedly stated that if his peers teased him, his 'thick skin' assisted him to brush it off and not be negatively affected. He mentioned his 'thick skin' thrice in the interview and stated that it was his coping mechanism.

> *To be honest I didn't actually have any issues with peers because I think my attitude towards a lot of things is that I'd laugh it off and brush it off. And if you're going to come and tease me about it, I'd probably tease you even worse about something else. I've learned how to fight back using words … spoken words more than anything. I'd fight mentally ... so it didn't really bother me.*

Shana's experiences and reactions were similar to Clive's. She indicated that she is an outgoing person who did not let people's negativity affect her. She further stated that she had close friends who were always willing to help her with schoolwork.

> *Some of the girls could be quite [profanity] but I just showed them that it would never affect me. That they could continue to be mean and I would just literally say to them I hope this is benefiting you and you feeling better for this because it's doing nothing for me or for anyone else. So, it never really got me down. I mean there would be days that I would be having a bad day and then someone would pick on me about it and it got me down. Throughout all the schools I went to, I got to meet different people from different backgrounds and I have a huge* [emphasized] *amount of friends.*

Kim, Jane and Stacey were greatly affected by peer reactions. They revealed their desire to be accepted and not judged. Kim was extremely critical and hurt by some of her peers but also pointed out that there were a few who treated her well: *The people who figured out that my reading wasn't great always made a point of reminding me how bad my reading was. But the people who didn't point it out were very kind.*

Kim stated that after attending the remedial school and then going back into mainstream education, she had befriended a girl who lived close to her and this had assisted her greatly.

> *I feel like if it wasn't for her, I would have had no friends and I would have been back in the same boat that I was* [at her first school]. *I didn't have any friends. I didn't make any friends because I was the poorest performing academic student in the class. Nobody wanted to be with me. Nobody wanted to be my friend. Eventually I made a friend. She left the country then nobody wanted to be my friend. Anybody who realised that I struggled to read did make fun of me.*

Jane's poor treatment and non-acceptance by her peers was visible in her facial expressions and tone of her voice as she recalled her experiences. Jane was the only participant who indicated that she was bullied, and sometimes by those whom she regarded as friends. She battled to find the words to convey the poor treatment received from her peers. She intimated that peers would make subtle comments.

> *Oh, you so stupid or you just adding a new two cents now or something. So, if they're talking about something and I just come in with something I think is a fact or just my opinion ... it's just. ... hard to get it across.*

Stacey also referred to the hardships that she encountered in Grade 8 as a result of being made fun of because of her literacy challenges. Her move from primary school to high school was especially difficult, and this was exacerbated by moving to a different city. The scars remained and as an adult she still has very few friends.

> *I never fitted in. I never had a best friend either. In Grade 8 especially I didn't have a single friend. In Grade 8 I tried to make friends. The group eventually swore at me and told me I was stupid. Then with no friends I couldn't go to the field and would sit alone because it was too embarrassing. So, I ate in the toilet very quickly because it's really gross to eat in a toilet. Then I went to the library and looked at books until break was over. I love the smell and feel of books. A full year of that was honestly one of the*

hardest things I've done, but it also showed me that I don't need anyone to make me happy.

Those with dyslexia are very aware that the challenges that they face makes them different. However, they desire to be accepted and not judged solely by their challenges. Whilst four participants did not allow their dyslexia to influence their interaction with peers, three participants have carried their negative peer experiences into adulthood with these experiences still affecting their interactions with peers.

5.4 THEME THREE – LIVING WITH DYSLEXIA AS AN ADULT

5.4.1 Family

Of the eight participants interviewed, two lived with their partners (conjugal family), three lived on their own, and three with their parents (nuclear family). This section discusses the experiences of the two participants namely Clive and Kim, who are presently living in a conjugal family, as well as the experiences of Jane, who has a partner. The family experiences of the others, who live on their own and are not in a relationship, remains the same as discussed in 5.3.1.

Clive's conjugal family comprised his wife and two young children under the age of eight. He stated that his wife accepted his dyslexia and was very supportive of him; however, he was of the view that she did not fully understand his challenges. Whilst she encouraged him to study for his matric certificate, her choice of the two subjects that would assist him in obtaining this certificate indicated that she did not fully understand his challenges. She chose accountancy and business economics for him to study, based on her being an accountant and therefore being able to teach both subjects to him. Even though computers were his forte, she did not select this subject.

I asked her why she didn't put me down for computers because I could do that quite easily. I really know how to use a computer, and then she said she didn't think of that.

Teaching accountancy and business economics to him was a very frustrating experience for both of them. No matter how hard she tried to teach him accountancy, he could not understand it.

I was unteachable when it came to accounting. I had no idea what was going on. I couldn't understand left to right ... its numbers ... the numbers don't make sense. You got

to put this in here and do that and ... So, the business economics side ... I managed because a lot of it was logic actually and I understood business.

He indicated that she could not understand why she was failing with teaching him accountancy and why he could not understand the work taught to him.

To her learning is ... she can't understand me at all. But for her I know she just buckles down, gets to it, concentrates, she can do all the work and she will push through it and she expects me to be the same. So, she would sit there and go right, this is this is that and I say but why am I doing it? Because you just have to. But no, I need to know why am I doing it? How come that goes there and that because that's ... that's how it goes, that's obviously how it goes ...

He failed his accountancy examination but passed business economics, which thankfully resulted in him obtaining his matric certificate. His view was therefore, that even though his wife was very accepting of his dyslexia, a full understanding of his challenges was not possible, when he can't understand it.

I don't think for a person like normal that can do reading and writing.... they don't understand why I don't know how to spell. I don't know why I don't know how to spell. I just can't do it. I look at a word no matter how many million times I've got to write that word down ... I can't do it again.

Despite not fully understanding his challenges, his wife fully embraced his strengths and challenges and did her best to assist him. She worked during the day whilst he was a stay-at-home dad, who worked on his graphic designing business during the mornings when the children were at school. If needed, he worked at night as well.

Kim was initially afraid to reveal her dyslexia to her partner. She was forced to tell him, when after losing her job, he encouraged her to study further. However, doing so did not result in any of the expected negativity that she was afraid of.

I said to him I'm reluctant to study something that's so reading dense because I don't know if I'll cope. He was like of course you will cope, just go for it and it eventually came out and I said to him ... you know, I'm actually dyslexic. I spell incorrectly, I read very badly and he was like ... well that's no excuse. Whatever it's going to take I want you to be happy. He's always made me feel good or comfortable. I told him because I felt like I

had to. But he didn't react with that urrrr you're broken next, and then he didn't. That was the end of this discussion.

She stated that she is a person who shows her insecurities, therefore such acceptance and understanding assisted her to embrace herself positively and hence her challenges.

What was really kind was that after that, he's never made me feel like it's a problem or it's bad. He's always been like hey this is tough for you; do you need help reading that or can I explain this to you?

Elation was evident in her facial expressions when she discussed her partner's attitude towards her dyslexia.

He's awesome. He doesn't see it as a problem. He sees it as a challenge that's not debilitating. It's not stopping me from being successful. He's always proud of me, always and he always tells me that he's proud of me as well. Every day he will tell me something good about what I did or something that he liked. He'll say you do this so well, you're so good at this. But I think that's just the way that he is.

Said with a smile and one of displaying pride, she was mindful that she also had her own strengths in areas that he did not. She viewed this as them complementing each other.

We bought a couple of furniture pieces that came with picture instructions. So there's no words on the instructions. You just have to look at the picture and figure it out. I can figure out the pictures. But he can't figure out the pictures. It's not his skill. But he also isn't the best at building. So any time we build anything I have to do the building and he has to try and figure out the picture which means everything takes four times longer than it has to.

Jane has been in a relationship for three and a half years and told her partner about her diagnosis immediately after she was diagnosed. He indicated that he did not know about dyslexia, but he was and is accepting of her diagnosis. Whilst visiting her partner, Jane was interviewed in his parents' home. His support, encouragement and acceptance were evident to the researcher.

He didn't really understand me, so he was just like what..... I didn't understand myself so then it was kind of just like we're learning it together.

Family experiences of those with dyslexia, who are no longer living in their nuclear home or who still live there but have partners, revealed that their dyslexia challenges are embraced and accepted. They are assisted with their dyslexia challenges and this occurs even though their challenges, whilst known, might not be fully understood by their spouses and partners.

5.4.2 Relationships with others – Social life

Clive disclosed that as a learner he had quite a few friends, but as a married adult he had no friends.

> *I had a close amount of friends, now actually people don't understand it. I got zero friends ... I don't have friends that I go and visit or anything like that. I've got my family, I'm happy with that, I don't need friends to go and visit. People sometimes annoy me. I'd be happy to be a hermit put it that way.*

He was however, very involved in his neighbourhood watch. He was one of the committee members and therefore liaised with this group nightly during his neighbourhood patrols, as well as in the various forms of communication that were used by this group.

Mary's dyslexia has not negatively affected on her social life.

> *I see my friends on a weekly basis, like three times a week whether it's with sport or just to get together with coffee or to bake together. I do see them quite a lot or on weekends we will go out together and on holidays. We will spend quite a bit of time together in the holidays, so I do have a social life. My dad's very concerned about the number.*

Walter and Shana indicated that dyslexia has never had an effect on their relationship with others and that they both have had a considerable number of friends. They revealed that they were outgoing and hence comfortable to interact with others, provided that they were not judged by them because of their challenges and being different.

Henry differed, in that whilst having friends and mixing with them, this interaction was solely on his terms.

> *I'm quite anti-social. I just don't like crowds. People are very draining. I get very tired of people. If I'm prepared for someone its fine, having unprepared visitors are the worst for me. I'll have like a quick conversation and then shoo him out just not to be rude. Even*

if they my friends, if they unprepared I'll sit with them for a bit and then go. It's just draining for me... it's very stifling.

Both Stacey and Jane's social life had been negatively affected by their peer experiences whilst at school. Jane, despite embracing her dyslexia, was very aware of others' views of her and has had a limited number of friends. This was further compounded by studying at an institution that required her to live on her own and in a different province to her parents. Stacey also indicated that she had very few friends. Peer experiences at school have had a marked effect on Stacey and Jane's social relationships as adults. Jane appeared to be satisfied with having her partner as her best friend, whilst Stacey's job as a chef on a yacht kept her occupied. Stacey indicated that her bad school experiences with peers taught her that she did not need peers to make her happy. This was stated with positivity, and indicative of surviving no matter what challenges she faced; however, she did not show despair or loss when stating this.

Even though peer experiences might have been predominantly negative for those with dyslexia when they were younger, the participants, as adults, have acquired coping mechanisms. These mechanisms have enabled them to make choices regarding peers, with such choices enhancing their happiness.

5.4.3 Tertiary Education

For differing reasons, Mary and Walter were the only participants who did not attend a tertiary education institution. Mary was presently studying for her matric certificate (Grade 12) after which she would decide on whether to continue with her education. Walter indicated that his computer skills had been gained through self-teaching, with the assistance of YouTube[7] videos. (The skills required for software analysis, graphic designing and website designing are usually acquired at tertiary education level.) Despite not having certification in these fields, Walter has had work experience in all three fields and was presently employed at a large computer company as a software quality analyst.

Stacey, Henry and Kim had studied at universities and obtained degrees. Jane completed a one-year psychology course at a college and was presently enrolled at a university where she would continue with her studies in psychology. Clive and Shana both left mainstream education at the

[7] A video-sharing website

end of Grade 10 and then attended private colleges. Here, Clive completed a short course in graphic design. He has worked in large companies as a graphic designer but was presently aself-employed graphic designer. Shana completed a short course in graphic design and printing, at a printing college, to obtain the skills needed to work in her family-owned printing business.

5.4.3.1 University

Despite their literacy challenges, Stacey and Kim and Jane selected psychology as their field of study. Whilst Jane has completed a one-year course at a private college, and was presently enrolled to commence her studies in psychology at a university, she indicated that she made the choice to study psychology because:

> *It is like observing people so it is very interesting to find out more about disorders and just about people and the whole thing about our brains and everything. It was nice because I understood it already. I have my own background on it.*

Kim disclosed that even though her matric results did not give her sufficient points to be accepted into university, she succeeded through a programme offered at the university for such students. After being accepted into the programme, she studied psychology as well as music, drama and performance. Stacey and Kim despite obtaining their degrees, left this field of study and continued their studies in what they enjoy doing.

Stacey revealed that she did not pursue her initial field of study and this was caused by her dyslexia.

> *After I finished my psychology degree, I did a chef's course. It was a full programme so not only a course ... a 4-year programme. This is where the dyslexia comes in. I enjoyed psychology but I needed my honours to continue, so I decided it wasn't for me. And I really liked cooking from when I was young so I decided why not.*

Kim continued with her studies after obtaining her degree and fulfilled her desire to practise as a personal gym trainer.

> *I have a certificate of group exercise from ... Society of South Africa, a swimming coaching certificate from ... South Africa, and a specialist coaching certificate from ... and a Sports science certificate from ... for personal training.*

Data revealed that the tertiary education fields of study selected by Kim and Stacey, whilst based on their interest and presumptions of what they would enjoy doing, played a very small role in their eventual job choice. They deviated from their primary field of tertiary study, with both indicating that their dyslexia challenges led to this change, where they chose a career that was more practically orientated. Henry however, differed and remained in his primary field of study. Henry and Kim's academic acceptance into university showed similarities.

Henry was determined to be accepted as an engineering student despite not having the marks to gain entrance into this field of study. Following the path offered to disadvantaged students, with his dyslexia placing him into this category, he eventually obtained acceptance. He followed a programme of study for a year which led to his acceptance into his chosen field of study. He has obtained a primary degree which includes honours, and was presently in his third year of study for his master's degree in mechanical engineering.

Stacey and Henry indicated that the universities that they attended provided concessions to them during their studies, granted after providing proof of their formal diagnoses of dyslexia and requesting the required concessions to be made. An extra 15 minutes per hour was given in their tests and examinations. Henry indicated that he was also provided with spelling concessions as well as a separate and hence private examination venue. Henry was very complimentary of the university that he attended and indicated that his matric results would have been far better if his school had assisted him with such concessions. Kim however, indicated that she did not request these concessions as she was determined not to be treated differently and to prove to herself that she could do it just like all the other students.

Despite the universities acknowledging dyslexia and providing concessions to these students, some lecturers were revealed as being negative in their treatment of students with learning challenges. These included comments about their handwriting, poor reading skills, being questioned about their acceptance into university and being ridiculed in front of all the students in the lecture. Private disclosure to the lecturers about their dyslexia revealed mixed reactions. Whilst it provided understanding to some lecturers, others showed a complete lack of understanding. The participants indicated this lack of understanding could be contributed to lecturers viewing the disclosure as the student providing an excuse, or as the student being lazy and not trying.

Kim recounted the negativity that she experienced from a lecturer who embarrassed her in front of the class.

> *How do you get into a university with zero reading skills? You're studying drama. The least you can do is practise your reading. That's how you get better at it. So after the class I approached him and I said look, I'm actually dyslexic, and he was like that's no excuse. You just have to practise. There's no other excuse. You want to study drama. You have to get better at reading. I felt like it was very unkind because I was trying to explain to him, I'm not lazy to try and read. I didn't come to class unprepared. I actually struggle to read and he heard that as I'm too lazy.*

The three participants who attended universities all revealed their determination to gain entrance into the university as well as their determination to succeed. Despite encountering negative lecturer experiences, following fields of study selected by them, as well as the concessions made for one participant, assisted greatly. Their university experiences and success validated that they had the potential to be successful.

5.4.3.2 Private colleges

After leaving school, Shana and Clive both attended private colleges where they did short courses to prepare and provide them with the skills needed in the workplace. These courses were funded by their parents. Shana studied graphic design and printing so that she could work in her family-run company, whilst Clive focused solely on graphic design. They indicated that they enjoyed their courses which were mainly practical and did not require them to write an examination.

After completing Grade 12, Jane registered for a one-year psychology course, which was funded by her parents. This course required her to do lots of reading which posed a challenge for her but did not involve a written examination. Determined to succeed, she put in many extra hours to cover the work often going beyond that which was required.

> *It was tough in the beginning because we get readings before the lecture so either you can either read them after or before the lecture. I always did mine before so I could understand more in class but I was never getting my readings done. So I went to the student advisor and he said no, it's not like an in depth reading because I was taking notes and highlighting. I would spend my whole mornings ... so I'd only have like a lecture at 11.45 am to 2.45pm and I'd wake up at 7:00 and from 8:00 I was just sitting at my*

desk getting all this information. So, I was burned out by the time I went to the lecture. I went to him for help because I was so scared, I was falling behind because I wasn't finishing my readings. He said no, you just have to like skim read. You don't have to read it in depth but if you're wanting to you can. He was very nice about that.

Jane further revealed a positive reaction from her lecturer after disclosing her dyslexia to her.

My lecturer in the first term didn't know I was dyslexic and her comments were very harsh and like sharp and straight to the point. I had her again in second term and I told her I was dyslexic. She actually showed a little bit more interest. She would ask are you doing okay and everything like that and I said yes, it's fine. Then my next paper she marked she commented a lot differently. So, it does hold because when she commented sharply it drains me because like I feel like uhhhh ... I don't know how to do it any different.

Shana, Clive and Jane did not indicate that any concessions were made for them at the tertiary education institutions that they attended, but neither did they indicate that they needed such concessions. This could be due to them having studied courses that did not have a written examination. Clive's demeanour showed that he enjoyed the graphics design course that he had selected to study.

90 percent of the stuff was taught in class practically which was awesome for me. You are put in front of the computer, the teacher stood in the front there and said ok click this button, do that do this push this and I was happy. There was some reading and writing kind of stuff. There was a written test but a very basic written test which I had to kind of study, but I liked the subject. I like computers and I liked drawing so I actually came second in class with like 92 percent. It was something I enjoyed and wanted to do, opposed to getting forced to do stupid things.

Experiences at private colleges were positive and this was mainly attributed to the participants choosing their field of study. Their choices were based on what interested them, what they enjoyed and where they knew they had the skills.

5.4.4 Workplace experiences and challenges faced

Shana and Henry indicated that both in their curriculum vitae (CV) and when going for job interviews, they always made sure to disclose their dyslexia. Despite this, Shana indicated that she has faced stigmatisation, where she was told that she was taking too long or making

constant spelling errors … *but then I just give a friendly reminder that I am dyslexic. I am trying my best and I did state so in my interview.*

Despite having worked in numerous places, she had however, never been labelled negatively by her co-workers. Clive made sure to disclose his dyslexia to whomever, when in the workplace, and expressed the same workplace experiences to that of Shana. His skills shown in the workplace contributed to positive workplace experiences.

> *When it comes to technical planning and the logical planning of stuff I love, I'd enjoy doing that. I would sit down and go ok let's move this here, let's do this, let's do that. In my previous works, I've had to plan entire factories where everything goes and organise that the piping gets put in and when, and I will go, you need to put that there, you need to do that there. To put that there mark out X, that's where this machine goes. Next machine ....*

Kim's negative workplace experiences are unique when comparing it to the other participants. She experienced stigmatisation, being labelled negatively, made fun of and being ostracised.

> *I can't tell you the difference between male as a gender and mail as in the post. I can't tell you what the difference is if I write the word on its own. If I say email than I know which one it is, and if I look at them ... still can't tell you which one it is unless there is an 'e' in front of the letter. So I'd accidentally made that mistake and they had such a laugh about it. She told through the office and showed everybody the email and they like uhhhh ... she said male like male person male. I said send me a male when you're ready and she came into my office. She was like you must be dyslexic or something and I said I actually am. She was like, that's hilarious, walked out the office, told everybody that I was dyslexic, and it sort of made everybody very different towards me. Everybody started double checking if I had definitely gotten my message correct. Or are you sure that's what they said or did you definitely read that, or don't get dyslexic on the numbers. It was actually worse as an adult in a working environment to be dyslexic, than it was at school.*

After the humiliation incurred, she then faced exploitation by her superiors: *You need to bring me a certificate for your dyslexia so we can claim your disability for BEE* (Black Economic Empowerment).

Six of the participants who experienced being in the workplace, referred to the work challenges as a result of their dyslexia. Stacey revealed that the major challenge that she faced as a chef was the concentration needed for reading the meal tickets and cooking at the same time. This was compounded by the duration of the service time.

Clive revealed that his challenges faced in the workplace were emails and price lists.

> *I'll get a set of numbers that I've got to literally type something out. If somebody sends me a 132, I'm going to probably write down 123. When I'm in a hurry somebody has check because it's gonna be wrong and I can guarantee if there's something wrong in there, I can't tell you where it is, no matter how many times I look at it. I won't be able to pinpoint the issues.*

He was currently self-employed and indicated that that his terms and conditions on his quotations indicated that his spelling and numbers must be double checked. However, to date he had never made an error.

> *Normally when it comes to those sorts of things I normally check and check and double check and then check again.*

Henry was a tutor at the university and indicated that work challenges included sending emails, writing on the board and power point presentations. As emails do not have corrective properties, he first typed his email in Word so as to use the spell check tool, and then copied and pasted it into an email. He prepared beforehand for lectures and referred to his methods of overcoming his challenges when lecturing.

> *I know my material. So, what I do is beforehand I just glance through it, like the morning or the night before, just so I remember all the facts and then prepare one or two equations. Half the time you can just solve the equations on the board but I don't read off PowerPoint slides. I generally just go unprepared or without PowerPoint slides, cause PowerPoint slides have stuff to read. So, I'll just go with a chalkboard and then if I have to write out a question, I'll have it printed out. I can just copy straight onto the board. I'm not going to just write something from my head. If I ever have to write something like a law I would have it typed out and in my notes, even though I don't actually use key cards.*

Walter confidently stated that whatever challenges he faced in the workplace, he did his best to overcome it without assistance from others: *If there's any information then I'd rather try and*

figure it out for myself because then I understand more, instead of somebody telling me this is how you do it. His work involved writing reports and this proved to be a challenge as well as time consuming.

> *We've either got to type up reports or actually write reports. So, if it's typing I do notice I put the wrong word... or I skip a word. So, I got to go back and read it first before I submit or save anything.*

Unlike Clive he was able, after careful scrutiny, to identify errors that he has made.

Whilst experiencing challenges and stigmatisation in the workplace, the participants' maturation, coping mechanisms and determination to succeed, despite their dyslexia challenges, was their driving force to believe in their abilities.

5.4.5 Adult challenges

Challenges faced as an adult included filling in forms, learner licence tests, and restaurant menus and for Clive his neighbourhood watch duties, when patrolling in the area. He indicated the challenges that he experienced when having to remember the licence plate numbers of a vehicle.

> *The vehicle is ND. I can't do that on a whim. I've got to really concentrate when I write it down. Try and do a little number rhyme thing, and the only way I remember it if I need to remember a license plate number I've got to go 32, 92, 62, 32, 92, 62. I've got to do that for a least 10 minutes before I can like write it down and get it correct.*

He further revealed that filling out forms is a major challenge; however, his wife would assist him if they were together at the time.

> *You going to have to do it kind of thing and I apologize 90 percent of the times while I'm doing it and I tell people look I'm slow it's going to be slow. If my wife is with me then she'll fill out the forms. When we were on the airplane and we had the two kids, we had to fill out these forms, and I basically took one of her forms and copied it. It is slower because I've got to concentrate a bit more.*

He disclosed his determination to succeed with his driving learner licence test that must be passed before learning to drive a vehicle.

> *The way that I learned for my learner's licence is I think it was from two weeks before I read the book. I went and read everything every day. Then the night before, I read the*

book and I did the little test at the back and I went and did the test and I passed with flying colours, but it was something I really wanted to do.

Shana revealed that sometimes she was able to overcome the challenges associated with filling out forms and that of her driving learner licence tests, by producing a letter from an educational psychologist and lawyer stating that she had dyslexia. Her signed letter of consent for this study reveals that writing was a major challenge for her, therefore necessitating such letters from specialists.

When I did my driver's learners licence I got a letter from an educational psychologist as well as a lawyer stating I was dyslexic in order to do my learners test orally. Then I have also been assisted at home affairs on a number of occasions by not standing in a queue and going to the supervisor or manager's office with my letter to say that I am dyslexic. So, I didn't have to fill out the forms.

She stated that restaurant menus are a challenge.

Going out to dinner one night with a new group of friends, I was sitting staring at the menu and I was just so nervous being around a new bunch of people and I couldn't read the menu. I remember being ashamed and embarrassed and I just put the menu down. I said to the waiter when he came, I'm sorry but I can't read the menu. Can you please tell me what on it? Everyone laughed first and then said why? Then I said because I'm dyslexic and I battle to read and write and then the waiter was very sweet about it and said give me five minutes and went through the menu with me and it became a topic of conversation. At first, I was very ashamed and embarrassed but I feel that the more I take power of it the better it's always for me.

Kim disclosed that she failed her driving learner licence test twice and that this was caused by her dyslexia challenges. She also made reference to restaurant menus.

Any time I go to a restaurant I'm not familiar with and I have to read the menu, I'm like how am I going to choose something to eat. I start scrambling for words I might recognise and then I calm down and I'm like ok it's just a menu. But that's my anxiety.

Walter revealed that even though he was slow, he overcomes his dyslexia challenges where he confused the letters 'b' and 'd' by always writing in uppercase. Filling in forms, menus and his driving learner licence tests were not too challenging as a result of his dyslexia not being severe.

Henry stated that he always tried to get a copy of the form that must be filled in and thereafter fills it in at home; for example, forms that must be filled in for applications made at the Department of Home Affairs, such as passport and identity documents.

Having lived with dyslexia for the greater part of their lives, coping mechanisms play a vital role in the lives of adults with dyslexia. Such mechanisms contribute to their acceptance of their dyslexia, thereby contributing positively to their happiness and contentment.

5.5 THEME FOUR – THE DYSLEXIA LABEL

This theme focuses on what the label means to the participants, their disclosure of it and their views of the use of the dyslexia label in society and education. It is deliberately placed and analysed after the first three themes of this study, as the participants' experiences herein are better understood and validated against the backdrop of the first three themes.

5.5.1 Participants' views

It is important to state that at the time of the interview, all participants had embraced their dyslexia positively and depending on the circumstances, they were not embarrassed to reveal their label. This was validated in their consent given to be participants herein. Hereunder is a presentation of the participants' views on their dyslexia label.

Whilst Stacey was accepting of her label, she was very mindful of the way in which people viewed her, based on this label.

> *I don't think that at all the dyslexia label is necessarily bad. I don't mind the label. But I do hope people understand it. I don't want to be thought of any less, but the label also gives me answers as to why I am not normal so I like that.*

Kim aptly summed up her label and the way that she viewed it: *dyslexia is a label that describes a condition of my learning. It doesn't describe anything else about me.* Jane's response was very similar to that of Kim's: *The label is not a description of the whole of me. It's just a description of a part of me. It's just a small aspect of me.*

Mary, as a result of having four older siblings who are dyslexic, embraced her label positively as a result of where she placed her focus.

> *To be honest with you, I don't have a problem with the label. I think there's soo many upsides to dyslexia and you just have to focus on them and to find a way to make it work for you.*

Shana's views of her dyslexia and hence the label was shown in many of her responses given during the interview. Like Kim, she was concise in her response to her view of her label: *I feel very comfortable with having the label of dyslexia.* Clive was also very comfortable and accepting of his label as it had answered many of the questions that he had about his challenges: *I don't really mind people thinking or labelling me as dyslexic. I am, too bad. I am ok with the label ... people call me dyslexic ... I am. I label myself.*

Henry never had a problem with his challenges, even prior to diagnoses, and this was evident in his views of his label.

> *The label is not particularly a negative thing, it's not a bad thing. I've got no problem with anyone knowing that I have dyslexia. Tell me one thing that's bad about the label of dyslexia.... you struggle with reading and writing. This is not the worst thing in the world.*

Walter differed from the others in his views of the label, but these views were influenced by his personal lifestyle choices, which he repeatedly associated with being labelled.

> *It's actually .... that's a tough question. But then again, I don't think it should be used because you shouldn't .... nobody should have a label. I feel that it's just a negative. It feels like you're putting me down. So, you say I've got dyslexia. So, what are you saying? I can't do what other people can do.*

Despite differing in their views on the use of the label, the majority of the participants viewed the label as a means of acknowledging the existence of dyslexia and the challenges that are experienced as a result. However, it is of utmost importance that others acknowledge that the label makes reference only to a small part of them.

5.5.2 Disclosing their dyslexia

All participants indicated that they had accepted their label and were not ashamed to disclose it to others. Ownership of the label and disclosure without any constraints were indicated by Mary, Shana, Clive and Henry. Their attitudes were indicative of "it is what it is and I have nothing to hide or be ashamed of." Clive aptly summed it up with a profanity*: s..... happens..... I don't think why me?* His acceptance and attitude were conveyed in his feelings regarding the use of the label, which is further discussed in this theme.

Jane revealed that whilst she was not embarrassed by her dyslexia and believed in the value of the label, she was comfortable using it; however, disclosure depended on the situation. She found it a challenge to fully explain her feelings towards disclosure.

> *I wouldn't like straight up introduce myself as dyslexic. I don't want to be identified as oh that's the girl who's dyslexic right. I wouldn't want that. I just want people just to know so I just don't embarrass myself in the way that they like uhhhh shame ... gee whizz ... like there's something wrong.*

Stacey displayed no hesitation in indicating her disclosure of her label.

> *I don't openly advertise the label but if I trust a person or if it makes things easier, I will. I've told my boss as well as only a few close friends and family.*

Mary felt comfortable disclosing her dyslexia to others.

> *I have told a lot of my friends. Especially since you talk over WhatsApp you are bound to make many spelling mistakes. So, I do say I'm sorry I'm dyslexic. My spelling is atrocious, it's terrible ... it's very bad. So, I don't have a problem with telling people. I have gotten not teased about it ... but in a way teased of it in the past, but I learnt that I don't have a problem with letting people know that I have dyslexia.*

Shana disclosed her label to others when she felt that it provided an explanation for her challenges or when she needed their assistance. This included disclosing it to persons who were unknown to her, for example waiters/waitresses or to persons in situations where she had to fill in forms. *The more I take power of it* [the label] *the better it's always for me.*

Clive was extremely forthright in his views of the use of the label. He believed that it should not be avoided, as it provided an explanation for his challenges.

> *I tell people I've got this issue and it isn't a case of I don't know how to spell, I don't know how to read properly, I can't, when I look at numbers, I mix them up. But if you can label it and go this is my issue, I've got dyslexia... do you know what that is? I can do other brilliant things but when it comes to this aspect, I need your help, and don't make fun of me. I don't really mind people thinking or labelling me as dyslexic. I am, too bad. I tell people the dyslexics are teapilpoo. So, it's a funny way of saying 'Are people too'. I don't know but it* [label] *does make it easier when you can just try and explain to people. Here this is it. I don't have to beat around the bush. I don't have to put massive labels on the thing. You don't have to go into massive detail. This is the issue. This is how I need help to deal with life kind of thing.*

Henry indicated that he had never been embarrassed to inform people that he was dyslexic because of his views about it and the way in which he lives his life.

> *It's not particularly a negative thing ...it's not a bad thing.* I *also tell people to tell me one thing that's bad about dyslexia. You struggle with reading and writing. This is not the worst thing in the world. I know that I am smart.*

His reason for disclosing it in his curriculum vitae (CV), was to ensure that prospective employers would be aware of the challenges that he might face and hence present.

> *The thing is you're highlighting it in a way where, because a lot of the stuff on dyslexia is either seen as someone does very bad academically or Einstein had dyslexia, and we want to link it to that one. So, I have dyslexia, but I got a degree in engineering. You want to link yourself with that positive, because a lot of smart celebrities you know had dyslexia. It's not just I have dyslexia excuse my bad writing. It's I have dyslexia.*

Despite having stated that the label is negative, Walter had disclosed his dyslexia to his work manager and to a few of his team colleagues. His reason for informing his team colleagues was however, not to provide an explanation for his challenges.

> *We were just talking about personal life and how school was ... this was when I started (his disclosure). So, they wanted to get to know me and how things were growing up and just the type of person I am [he revealed that he has dyslexia]. I've got no problem with it or telling people.*

As revealed by Walter, whilst stating that labels are negative, his responses appear to indicate indecisiveness about the label, which was impacted on his lifestyle choice. He often made reference to him being labelled because of this choice and therefore saw all labels as negative. He however, indicated that he had no problem disclosing his dyslexia label to others.

Kim was selective about to whom she disclosed her label as she was afraid that people would judge her, solely based on the label. Kim used her discretion and innate feelings to guide her disclosure.

> *As long as I feel safe to do so, like you're* [researcher] *a very safe person to talk to. I don't feel like you're judging me. I don't feel like you're trying to put me in a box and go oh cool, ok label there you go. I don't feel that that is your intention which makes me feel comfortable with you. Some people you can just see that no matter what you say to them they've made up their mind and they're going to think what they going to think and you can't do anything about that.*

Participants indicated their acceptance of their label and not being ashamed to disclose it to others. However, disclosure was dictated by circumstances and the need for disclosure.

5.5.3 Societal and educational institutions attitudes and use of the label of dyslexia

The majority of the participants were of the firm view that the label of dyslexia must be used and not avoided. Kim and Walter were however, indecisive in their views on the use of the label. Both experienced being diagnosed with dyslexia whilst in primary school with their diagnoses not being revealed to them.

5.5.3.1 Society

Whilst most of the participants embraced their label, society's ignorance and viewing of the label of dyslexia was referred to. Societal ignorance was viewed as contributing to the stigma placed on dyslexia.

Clive stated that he has never been labelled or ridiculed by others because he had labelled himself. *It doesn't bother me at all. I prefer it... people call me dyslexic... I am.* He referred to people's ignorance about dyslexia.

I've had people going like oh that kind of thing and show surprise. And some people laugh like I'm telling them a joke. I think a lot of the times people do think I'm joking around. They don't know what I am talking about.

He however, pointed out that people joke about them having dyslexia, when they are not, as a means to provide an explanation for their errors.

People will joke around if they mix things up in like a spoonerism. They will say ahhh sorry dyslexia kind of thing ha. But they don't fully know what dyslexia is. So, it is sometimes used as joking around.

Henry was very aware of the statistics surrounding dyslexia with it being a common learning challenge. He stated that the root of the stigma surrounding dyslexia was people. He felt strongly that the label must be embraced and used, as doing so would decrease the stigma and negativity that surrounds dyslexia.

A lot of problems are actually caused by people just trying not to label the problem or address the problem. If you start calling dyslexics, dyslexics I can almost guarantee that when everyone hears it, it's no longer a label. If you deal with it every single day, it's not going to be a label. People might use it in a negative sense but using it often will turn it into a positive. So, the word is not negative or positive and that's a big thing.

He used the example of ADD where people know about it as a result of it being commonly used, and hence accepted and not avoided.

ADD is not seen as a massive negative anymore. Now its people making jokes about not being able to pay attention and no one's really using it in a sense to mock someone directly for being ADD. Using the label is a way of making the label known, because the label exists no matter what. We've got to find a way of making it into something that's a lot more difficult to use in a negative sense.

However, he was of the view that societal ignorance surrounding dyslexia has improved. Like Clive, he showed extreme agitation towards those who casually make use of the word dyslexia as means of providing a reason for their mistakes. *So many people use it to just excuse them for doing this or that.* His coping mechanism when facing ridicule from people was: *If someone mocks dyslexia ... well it means I'm smarter than most people. I just can't read or write it's ...*

Kim's views of societal feelings and reactions to dyslexia were protracted and very influential in her life. From her answer which she unhesitantly provided, it was evident that her feelings towards society have dwelt with her for a long time

> *I wish people understood that being dyslexic doesn't mean stupid Dyslexic means difficulty with reading. That people would be a bit more understanding, that it's not a learning disease. You don't have a problem if you are dyslexic, you have a difficulty. What has happened is somebody made it sound way more serious than what it is, because I obviously don't believe that dyslexia is a super serious condition. I don't think it's something that is debilitating and that's a word that was once used to describe it. I've heard people say horrible things about dyslexic people. Any sort of difference or anything that's sort of sets you apart ... it's not. I think if I had to say something to describe it, I would say don't put it as a disorder or a condition. Think of it as a classification of existence. You exist under these circumstances. Doesn't make you a bad person, doesn't make you a poor learner. It doesn't make you insubordinate, it doesn't make you stupid. It doesn't make you disobedient. It makes you .... have brown hair.*

Like Henry, Kim was also of the view that ADD and ADHD do not have the stigma attached to it like dyslexia has, because of it being used and not avoided.

> *If dyslexia is spoken about as freely as ADD or ADHD people will understand it better. I don't think people realise that dyslexic people are abnormally smart. If you can attach some kind of good to being dyslexic, people would be like you know its ok. I'm dyslexic ... it's tough because I battle when I read. But I'm okay with it because it's not hurting anyone you know. So not breaking anything and not hurting anyone I'm not hurting myself.*

Jane indicated that people are not sure about dyslexia and this leads to them thinking that the label reflects something being wrong. *Like there's something wrong. I want them to be more understanding towards it.* Societal ignorance was reflected in her partner's response to her diagnosis, where he admitted that he did not know about dyslexia.

Stacey however, stated that sometimes the label is a problem for her.
I feel like people assume things about me or think I am making up excuses when I battle to do something. But I really think it's about what you make out of it and I want to be normal on anyone's standards not just my own.

Shana believes that it was very important for the dyslexia label to be used, *so people can get a better understanding of you.* Shana and Henry stood firm in their belief that the label must be used and this is validated in their label and hence dyslexia diagnosis being included in their CV. Shana indicated that she included it as she was not ashamed of her dyslexia status and felt very comfortable with the label of dyslexia used on her as it provided a better understanding of her and her challenges. Henry further revealed the following about the inclusion of dyslexia on his CV:

> *It's not direct. It's shining dyslexia in a positive light. When they come to what are your qualities, I say overcoming problems because I am dyslexic because I couldn't do this. I've overcome it and I've gotten to this stage. I don't think anyone should just put it in their CV just as a just, because again that might be a negative thing. You shouldn't omit it because that's wrong. But you should put it in a light that makes it seem positive. With a CV, you've got to spin it into something positive always.*

Mary believed that societal ignorance can be overcome if society is educated or informed about dyslexia and that the names of famous and successful persons with dyslexia are highlighted. She was of the view that whilst these people's accomplishments are known, their challenge of dyslexia is not known by many: *Looking at Richard Branson, Steve Jobs and all of those top people we know that have dyslexia ... knowing that makes it a whole lot easier.*

Shana also referred to societal ignorance regarding dyslexia and stated that: *Informing others and also educating others about dyslexia can take away the stigma that's associated with it.* She laughingly referred to such ignorance as sometimes benefitting her.

> *Being dyslexic isn't all that bad. I mean it's benefitted me a couple times. When I did my driver's learners licence I got a letter from an educational psychologist as well as a lawyer stating I was dyslexic in order to do my learners test orally. The guy that tested me... I don't think he knew what dyslexia was ... and he was pitying me, and thought it was a disease and that I was going die.*

Walter believed that the stigma associated with dyslexia cannot be averted through educating people about dyslexia or through the frequent use of the label. However, Walters's answers appeared to be connected to extenuating circumstances in his life. These circumstances are known to the researcher and have resulted in him having a disgruntled opinion of people.

> *I don't think educating people about dyslexia or through the frequent use of the label will change the way it's seen. Everybody is going to have their own opinion. It's like everything that's got stigma attached to it ... it's only people in a certain group that get it and that's a stigma. So, there's a lot of information about saying it's not but people still believe that. I mean you can lead a horse to water but you can't make a horse drink.*

Societal ignorance regarding dyslexia is referred to by all participants and is viewed as contributing to the stigma surrounding this learning challenge. Therefore, most of the participants were of the view that society must be educated about dyslexia. They further revealed their views that the label must be used as a means of reducing the stigmatisation and assisting others to become more knowledgeable about dyslexia.

5.5.3.2 Educational institutions

Although the participants did not agree unanimously on the use of the dyslexia label with Walter indicating that he did not like the use of it, all participants viewed the label of dyslexia and hence its recognition as being of vital importance in schools. Participants were questioned about whether schools should use the label of dyslexia or simply view these learners as having additional support needs.

Clive was very forthright in his answer and did not hesitate, think about the question or try to find the words to convey his feelings. He was of the firm view that the specific label of dyslexia must be used in schools and not that of having additional support needs. *If you're not dyslexic what are you? Am I stupid? How do you not label it?* Clive was of the opinion that failure to use the specific label of dyslexia had negative consequences because ultimately indirect labels result as well as incorrect school and teacher views. He indicated that because the label of dyslexia was not used or acknowledged in schools that: I don't think I was ever called an idiot or stupid or things like that. But you definitely get a sense *of like put him in the slow bus because that's where he's going to need to go.*

Mary's views of the label are set against her being in a protected environment as a result of being home schooled. However, when questioned on her label choice being that of additional support needs or dyslexia, she indicated that she preferred the label of dyslexia.

> *I think I would prefer it that Mary has dyslexia, purely because the remark that Mary has additional support needs makes you sound that you're not smart. Or that you are not smart enough to be the same as the other kids and make it work. In the case where it's just dyslexia, you know you have it, but you are still able to learn in a special way to get help from it. I think having dyslexia would be better for a person. I mean I've never been in a school or anything but if I had to put myself into that position, I think I would choose dyslexia.*

Henry was also very emphatic in conveying his views of the use of the label in schools. When asked if the label should be used his reply was:

> *Yes definitely. The big thing is there's two ways of treating a label. Like if you own a label versus being called it because dyslexia is a word and it's gonna be used no matter what now. If you don't put it as a label where you control whether it's positive or negative, that could be bad. For example, no one can be called dyslexic in class. What are the bullies gonna do behind the bushes? They're going to call people dyslexics, whereas, if you just make it an acceptable term, it's a lot more difficult to spin it into something negative. You've got to control how it's used. It's one of those things. Like ADD, because so many people have used it, it's not seen as a massive negative anymore. Because the label exists no matter what, we've got to find a way of making it into something that's a lot more difficult to use in a negative sense. And I just think it's one of those things where you want to control what it is versus someone else putting it in a negative light.*

Based on his experiences, he provided his reasons for why the label of dyslexia must be used and not that of additional support needs.

> *With me when it was unspecific or called learning difficulties, I had such problems because they were trying to teach something that wasn't helping. Whereas when I got something specific, it helped.*

Stacey, whilst feeling that the label was not necessary in the workplace, viewed the use of the label in schools as important.

> *I think it's really necessary in schools, because it's also a gateway for the teachers to pinpoint actually what is wrong with the child or what the teacher should be aware of. It might not be necessary later on in life when you have a job but when you're in school, then we can actually pinpoint what is the disability.*

Walter viewed the use of the label in school as possibly being of assistance to him: *It might have helped if I understood what it* (dyslexia) *was and what the symptoms are of it were, because then I could understand why I was doing something.* Whilst not embracing the use of the label of dyslexia, he was of the view that the word dyslexia be used to describe his learning challenges and not the term 'additional learning need' as *'Additional learning need' could mean so many other things. At least if it's got a name you know what it is. Rather call a spade a spade instead of saying a learning need.*

Kim indicated that she had been labelled by her teachers, lecturers and peers. Labels frequently used on her were being called stupid and lazy. Despite this, Kim, who only recently became comfortable with disclosing her dyslexia to others, and hated the word dyslexia, was not in favour of having any label attached to her. She was the only participant who had these negative feelings towards the word.

> *How much more of an insult do you need* [to have the label of dyslexia)]? *I don't even know reading disability would be something more acceptable. It almost feels like when you say disabled.*

Shana stated that if schools embraced and used the actual label of dyslexia, she would not have changed schools like she did. Changing schools often were her parent's attempts to find a school where she would be happy. If schools acknowledged and used dyslexia then she would not have left school at the age of 16. The decisions made at school caused by their failure to acknowledge dyslexia, affected her negatively and she reflected her astonishment at some of the suggestions made by the school.

> *I kind of ran out of schools to go to. Going to so many different schools I didn't want to. Some had even suggested that I'd go to (....) the school for the deaf and I was ... I don't understand, I'm not deaf.... There was another one in Durban that was a school for disabilities. But I didn't want to go to any of those schools. And then my Dad just*

sat me down after Standard 8 (Grade 10) and said to me we've got a choice. I'll either find a school for you to go to and you can go and finish or you can go up to Johannesburg and go to the (name) College and learn how to run my business. And when you finish come back and run one of my businesses for me. So, I chose that option rather.

Jane was also in favour of schools using the word dyslexia, not denying its existence or using the words additional support needs. Like Shana, she was also 'forced' to leave the school she was attending, because of their reluctance to acknowledge her dyslexia, assist her and make the needed concessions for her.

And then .... [Director of the dyslexia association] *messaged them or emailed them directly and explained what dyslexia is and said that I have it and that I needed 15 minutes extra per an hour in exams. And so, they didn't want that. They said they'd only give me 10 minutes and this is the reason why I left. They weren't understanding about it at all. I didn't need any sympathy or anything, I just needed understanding and just like support from them and they didn't really show that at all.*

Participants were unanimous in their views that the word 'dyslexia' must be used in schools to describe the challenges that they face. Failure to acknowledge dyslexia and use of the word, whilst using other terms, were viewed as failing the learning needs of those with dyslexia. Participants viewed the alternative terms used as being negative.

5.6 THEME FIVE – MOTIVATIONAL EFFECTS OF LIVING WITH DYSLEXIA

All participants' basic needs which comprise their physiological and safety needs, are met. Their belonging and love needs have been discussed in the above themes. This theme focuses on their self-confidence, self-esteem and goals, with all impacting on self-actualisation, the top tier of Maslow's Hierarchy of Needs. Self-confidence in this theme is viewed as that which is displayed on the outside and therefore what is seen by others, whilst self-esteem is that which is inside and hence felt and experienced by the individual (Murray, 2018).

5.6.1 Self-Confidence

Self-confidence is derived from knowledge and practice and is displayed in trusting your abilities to be successful at new opportunities, challenges and tasks (Murray, 2018). The self-confidence of the participants herein focuses on that which is displayed outwardly, namely the

confidence shown in their abilities in the workplace, forming friendships, and public speaking. Mary (18 years old) and Jane (20 years old) are the youngest participants and are at opposite ends of the confidence spectrum.

Jane was the only participant who showed an almost complete lack of self-confidence in all three domains mentioned above. This could be attributed to her educational experiences. Her entire demeanour during the interview displayed this lack of self-confidence. She appeared to be emotionally scarred from her negative experiences resulting from her late diagnosis and the lack of understanding shown to her as a learner. She was the only participant that expressed this in both her words, tone of voice and mannerisms when questioned about her confidence. She indicated that she loves swimming and kicking a soccer ball: *I feel more comfortable with that stuff ... I wouldn't say like confident or like over flowingly out there but...just be a bit more comfortable.* When questioned about what she felt confident with, her reply indicated what was observed by the researcher: *I'm really not confident ...*

Mary showed absolute confidence and self-belief; however, this can be attributed to modelling herself on the success experienced by her siblings, who have achieved despite their dyslexia. She further indicated that knowing the names of famous successful people with dyslexia inspired her confidence: *Look at Richard Branson and all of those top people you know. We know that we have dyslexic. Knowing that they have it makes it a whole lot easier.*

Mary's confidence was boosted in her outlook towards her dyslexia

> *I think there's so many upsides to dyslexia and you just have to focus on them, and to find a way to make it work for you. If you don't and you believe that you have a problem, then you will have a problem. Whereas if you believe that you have dyslexia and there's upsides to it, you'll have dyslexia but you will have upsides to it. It's that basic.*

Her confidence was shown in her having left home schooling at the end of Grade 3, running her own small businesses and then returning to formal schooling in Grade 11. Her lack of formal education from Grade 4 to Grade 11 was confirmed by her mother, to whom I spoke. Both Mary and her mother were of the view that she was being indirectly educated through the small businesses that she owned. Mary is currently studying for her matric (Grade 12).

All the participants except for Jane showed self-confidence. However, despite this, Jane, together with all the other participants did not view their dyslexia as preventing them from achieving.

5.6.1.1 Reading aloud and public speaking

All participants, except for Walter indicated that their confidence was negatively affected if they have to read out aloud, especially if they were unprepared for it. Kim, whilst lacking in confidence for reading aloud, showed extremely high confidence in public speaking. She studied drama at university and was a member of the local theatre club where she had appeared in many plays.

> *If I've got to read anything I panic. I don't mind reading to myself, but I avoid having to read out loud by all means possible. Even today I will do acrobatics to avoid reading. I will do anything to avoid reading out loud. I also avoid, you know when someone says read this joke and then I'm like uhhhh* [she made a shrill sound]. *Then I try to gauge how many words are on what I'm looking at, or how long it should take me before I laugh at the joke, while I keep reading after I have started laughing.*

Clive indicated that whilst he was embarrassed to read out aloud, he had no problem with public speaking.

> *Reading was embarrassing. It was like I wasn't able to. I knew I wasn't able to read out aloud and that would make me nervous when it was my turn to read and especially in high school. You should know the words, but then when you're sitting there and you start..... I'm not afraid to get up in a crowd of people and talk. I'm not a nervous person I'm not afraid to do those things, but to know that you have to read something or do something on the board, write it or something like that, it would be stressful.*

Even though Henry was a very confident person he indicated that unprepared reading was a major challenge for him.

> *I think in high school occasionally when you have to do prepared reading, it was especially difficult for me. But then again it came down to memorising it rather than reading it out. Its unprepared reading that was very, very difficult. I think that was the most difficult. There was apprehension because your reading is really not that great and then having unprepared reading thrown at you in front of eeeeeeeeeeverybody* [emphasized] *not the greatest. You sort of hang back, when there is something to read*

aloud and blend into the background. You don't want to get called out for that because you're not particularly good at it.

Shana avoided and hated reading in public, but was not afraid of public speaking: *To this day I'm not a big fan of reading out aloud to anyone and it takes me a lot to... I've got to be very comfortable with a person to be able to read out loud to them.* Mary's feelings about reading to others were similar: *I try to avoid it but not to the fact where I would refuse. Say someone asks me to, I would tell them I have dyslexia but I'm warning you.*

Walter believed that because his dyslexia was not severe, reading was not his fear as much as public speaking.

I do struggle with public speaking. I get really nervous that I start shaking. I did drama at school to try and get over that. I think it has gotten better. I've got no problem talking to my team of eight. I've got a problem with a number of like 60 plus.

Stacey, like Walter, indicated that she did not like reading aloud and was afraid of public speaking.

For most of the participants, whilst reading aloud was a challenge, public speaking posed no problems for them. Walter was the only participant to express the opposite feelings to the others regarding this.

5.6.1.2 Workplace

Walter displayed extreme confidence in the workplace which had been proven by him having taught himself the skills involved with webpage design, graphic design and software analysis. This confidence was further displayed in the way in which he approached new aspects at work.

I don't like asking for help which can be a down ... a flaw as well, especially when there is time constraints. That's why like here at work ... if anything new pops up I'm gonna put my hand up to say I want to do it. [Asking for help] *It depends, is there time constraints or do I have time to figure it out? I'd rather try and figure it out for myself, because then I understand it more instead of somebody telling me this is how you do it. Asking someone is the easy way ... but then what if it comes up again?*

As a result of the success experienced in the workplace Walter was a confident person because of all that he had achieved. His present job was the result of him being approached by the firm and not him applying to work there.

Stacey's overall confidence was displayed throughout the interview and had been assisted by the work choices that she has made. She was passionate about the work that she did and indicated that it was her talent that boosted her self-confidence.

> *It's been 10 years since I went to school and after that I didn't really need those skills ... as a chef.*

Clive was a fairly confident person, depending on the situation. With regards to his work, he knew that he was good and was very confident in his abilities. He showed pride in recounting his skill in designing T-shirts and new uniforms for two popular food franchises.

> *If you go into ... it's all of my creation. What they wearing and everything from the buttons to the patterns. The guys would say ok, this is what they need done. You go, you design and I'd take a week or two and while people thought I was doing nothing as I'd just walk around and kind of stare into space. While I'm staring into space, I'm going ok this little thread there, that bit there, put that there, that's the colour that's this, this, this. And I'm trying to jot it down on a piece of paper.*

With pride he spoke about his excellent memory that has enhanced his confidence in the workplace.

> *I've got a very good memory when it comes to my artwork. But I think it's something I enjoy doing. I am able to draw logos and stuff like that. My job was to kind of redraw logos and I was able to remember every single logo that I'd ever drawn and people would say when did we do this logo and I said it was done in August 2013. Look in this folder it should be there under ... and we did it for this person kind of thing and the fonts was Arial Bold. I enjoy fonts as well as different shapes and how that all works.*

However, the confidence experienced in the workplace was lacking as a learner wherein he gave up trying to learn and failed his matric as a result. His confidence as a learner was negatively affected because of the lack of understanding of his challenges and being unable to study the subjects in which he excelled.

Kim exuded confidence in her varied abilities. She was a personal gym trainer, an accomplished dancer, violinist and showed skill in baking and cooking. With pride, she spoke about her strengths and the negative effect that this can sometimes have on others in the workplace.

> *I am a strong personality and. I think she* [work colleague] *feels threatened by that. So, she does constantly have personal attacks on me for it. I feel like I'm tooting my horn when I say that dyslexic people are abnormally smart. I know I'm clever. I know because I've succeeded in everything that I've ever tried to do, but I think my mom has a lot to do with that. Yeah, I understand things very quickly. I know what's going to happen very fast. I can figure stuff out.*

Despite her age (18 years old), Mary had run successful businesses.

> *I did an egg business at the age of seven. That was the main business and then we moved from the farm so that obviously stopped. But I've done other businesses... herb businesses. I had a lot of space in the garden so I had a big herb garden. I sold herbs to the health shops around and basically just natural products.*

Shana also showed confidence in her abilities in the workplace. She worked in her dad's printing company for two years and then left as she was determined to create her own success. Since then she has run a backpacker's institution, was the producer of live events, and managed an adventure centre. She was currently the manageress of a restaurant.

All participants with workplace experience show high levels of self-confidence. This could be attributed to them selecting places of work based on their interests and skills. It could be further attributed to their determination to succeed.

5.6.1.3 Interacting with others

Walter displayed confidence when interacting with others.

> *I've got friends... go out.... mix easily. I'm definitely a people person. I can easily just walk up to someone and greet them and have a full-on conversation. I met someone that was here for a wedding and we just met up for a drink and everything was fine. I didn't know him from a bar of soap.*

Mary knew that she was a confident person and acknowledged it:

> *I would say I'm a confident person. I don't with all areas but with socializing I am, and with being confident with who I am.*

This confidence was further shown in her having many friends and interacting with them on social media platforms where her dyslexia sometimes presented challenges.

Shana's confidence in interacting with others was evident in her selection of jobs that she has had thus far. Since leaving the printing company all her jobs have placed her in a position where she has to interact with others on a daily basis. She indicated the positives of moving to different schools throughout her schooling tenure: *I got to meet different people from different backgrounds and I have a huge* [emphasized] *amount of friends.*

Clive's lack of interacting with others was based on choice and not caused by a lack of confidence.

> *I had a close amount of friends. Right now ... actually people don't understand it I got zero friends I don't have friends that I go and visit or anything like that. I choose it. I've got my family; I'm happy with that. I don't need friends to go and visit. People sometimes annoy me. I'd be happy to be a hermit put it that way.*

Whilst Stacey was confident with people and was able to confidently interact, she too indicated that she had very few friends, but this was out of choice. She met new people regularly and interacted with them as a result of her job.

Henry's confidence has been referred to in the various themes already discussed. He mentioned that he knows that he is smart 12 times in the interview and that he is clever 3 times. His confidence is further boosted by his academic achievements, despite his not having been accepted for study at the local university, and thus realising that his intelligence has impacted positively on his self-confidence and self-esteem.

With the exception of Jane, all participants' interactions with others were not negatively affected by their dyslexia. They were therefore confident when interacting with others.

5.6.2 Self-esteem

Murray (2018) views self-esteem as the way in which individual's views themselves irrespective of their achievements and abilities. It is therefore the value or worth that individuals attach to them. Murray further states that persons with a positive self-esteem do not rely on their achievements to define them, as they are defined by knowing their value and worth. Looking at the data it was evident that Henry had a positive self-esteem. He had never allowed his literacy challenges to negatively affect him in anyway and believed in his intelligence. This even when he could not read and write.

A positive self-confidence does not necessarily result in a positive self-esteem. This was particularly evident in Kim, during the telephonic conversation that I had with her to explain this study. She exuded confidence throughout. The interview however, revealed that whilst she portrayed herself as a confident person, she faced an inward battle with fears of rejection, which impacted greatly on her self-esteem. Whilst being confident in her abilities she lived in fear of being ostracized and rejected.

> *I'm constantly terrified that the people that I interact with are gonna find a reason to either not include me or push me away or find a reason not to like me. I always feel like once people know that I'm a poor reader they're going to decide that they don't want to be anywhere near me. They're going to decide that I'm not good enough. They found a reason why they don't have to be my friend anymore and that's it. Forever.... It's finished now. It's probably the biggest anxiety that I have that affects my self-esteem.*

She experienced this lack of self-esteem daily.

> *Every time ... (her fiancé) leaves to go to work I feel like what if he doesn't come home because he doesn't want me anymore. You know I've always felt like ... not accepted even though I am. I'm very well liked by my friends and I know this but in the back of my head it's always something I've always felt that I'm just a little bit outside of your group. And I think that's why I'm so loud and so like...*

Mary revealed that at this stage in her life, her dyslexia did not negatively impact her self-esteem.

> *It was at one point when I was 13 and 14 and I was starting to mingle with the teenagers and going through that teenage phase, my self-esteem was affected and I became quite shy at times. At that time, I think I was not so much as brave with it ... you know when*

you want to be like this cool person. Yeah, I did go through a phase where it did affect me but not for long.

Walter also indicated that his self-esteem had improved with age.

When I didn't understand what it was and I thought something was wrong. But as I got older and I sort of understand it more and I just want to prove people wrong, my confidence and self-esteem has gotten better.

Shana stated that as a child her self-esteem was negatively affected but as an adult, and especially since she has learned to read, she believes in herself and her abilities.

Jane felt that her self-esteem had improved with her getting older; however, it was evident that her self-esteem has been negatively affected.

I really think it's changed, like I still doubt myself a lot and more like second guess. I still won't really ask questions [when she is with her peers]. I'll never do anything to..... if we in a group I'll never try like be in the centre of attention I always just rather be in the background.

Clive viewed his self-esteem as being affected by the task at hand, but was of the view that he did not allow his dyslexia to define and hence negatively affect the way in which he viewed himself.

I know that I'm smart enough. There's just this one part that I'm not good at. I'm able to do a lot of things. Yeah, I know I can. Dyslexia ... it's just like just a part or aspect of me. It's a thing ... it's I've got blond hair or I've got black hair. I've got dyslexia. That's it. It doesn't really affect me.

Stacey expressed that dyslexia had not impacted negatively on her self-esteem because of the choices that she had made.

I think if I was actually a psychologist and I wanted to become a clinical psychologist and I had to go through all that ... I think it would put my self-esteem down.

Whilst the majority of the participants were self-confident, this was not found with self-esteem. Whilst self-esteem has improved with some participants as a result of maturation and acceptance, this has not occurred for Kim and Jane.

5.6.3 Goals

Despite some participants indicating that their self-esteem had been negatively affected by their dyslexia, the goals set by them showed little effect of that negativity. The participants showed passion when revealing their goals.

Although indicating that she was not a confident person, Jane had set a few goals which she hoped to achieve. *I've always dreamed of working with animals. But I'm also want to do counselling or like psychology and work with people.* Jane's desire was to tutor children or be a counsellor as she felt that, because of her challenges, she would have empathy for those whom she tutored or counselled. However, her greatest passion was animals. Her passion would be to do a course where animals could be used for human therapy.

> *It's counselling. I'm mainly thinking about going to teens or I don't know what age to bracket. So, you're just using the animal, because animals naturally, just like you patting them. It has been shown that doing this ... your stress levels, anxiety levels, blood pressure all go down. So, and it gives off a relaxing hormone and happy hormone and that's just by patting a dog or animal. So, by using that, you kind of create like a more relaxed and comfortable environment for whomever you're talking to. Through that they open up more, sometimes unconsciously open up more because they're feeling more comfortable as well. With younger children, they will speak to you through the animal because they don't want you to know they're talking about themselves.*

From this it was evident that Jane had given much thought to her goals and achieving them and her confidence herein was evident.

Despite Mary being 18 years old, she had already had a few small businesses since Grade 3. Much of her confidence had been instilled in her by her family and she had given much thought to her goals which she aimed to work on, after the completion of her matric.

> *I would like to start my own business instead of finding employment. In the sense of being in South Africa. I love South Africa but I think I would love to travel. So, having a business that you can sort of take with you that would be great.*

At the time of the interview she had commenced working towards her goal of having her own business on a bigger scale than what she presently had.

> *I serve and cultivate ... or ... It's natural like probiotics. It's a natural drink. So, I got a few businesses there ... I make that and then I sell that and that's going quite well. And*

then I'm wanting to restart the herb garden.... I haven't had one in a while because I've moved so I haven't got that out of my mind.

Kim's desire was to gain entry into medical school. She revealed that her mother and fiancé were the only persons whom she had informed of this.

As I've spent time in the sports science industry, I've started thinking a lot about orthopaedics and orthopaedic medicine and preventative exercise protocols in athletes that are not currently being researched. Dances are very under researched and I really think that many dance injuries can be a hundred percent avoided. Currently I'm a personal trainer with a couple of years of experience. So, I've always been drawn to medicine. My grandmother asked me when I was seven what do you want to be when you grow up and I said I want to be a helper. I just feel like I've reached this point in my career where I've done a lot. But I'm moving laterally at the moment and I need something else. I need a new challenge. You know everything in my whole life has being sooo hard. That right now when it's not actually that hard I'm finding myself a bit bored. So, I've decided to apply to study medicine and I'm terrified. It's very hard. It's a very difficult degree, number one, and number two, at this stage of my life. I'm 30 years old.

She was however, aware of the challenges that her dyslexia posed in achieving her goal.

I don't know how well accepted I'll be and I don't know if having a learning disability is going to affect my application. But I'm going to try anyway. But I also feel like if I can do this, I will have validated every hope and every dream and everything that I've ever enjoyed. If I can do this... it's not a status thing for me to be like awww I want to be a doctor. I don't want to be a doctor. I want to be a helper. You know I feel like this is something that I can do. It's more and more ... it's like this bell that keeps ringing louder and louder and louder.

Shana's present goal was to relocate to another country and open her own restaurant. She was in the process of achieving this. Walters's goals were directed to his work. He aimed to continually learn and to gain as many computer skills as he possibly can. Clive was of the view that his goal was to be self-employed and successful. He had achieved this by owning his graphic design business and having large franchises as his customers. Apart from this, he indicated no further goals. Henry's present goal was to find employment as an engineer; however, achieving this was not affected in any way by his dyslexia, but was affected by the lack of job availability.

Stacey was the only one who indicated that she did not really have goals.

> *I think I feel the same, frustrated. I know I have an official disorder and I know I'm not crazy but at the end of the day it's not something you can see like a wound. So I still think deep down I think to myself that it's in my head and I'm just lazy. It's a very strange scenario and it's hard to get someone else to understand. But I know I am not crazy but I also know that I feel like I have a limiter on myself. It feels like those speed things on the car. And mine is stopping me from going faster than 80km/m but everyone else can go 140km/h. I know I can go to 140 km/h but I just don't know how to do it.*

However, despite this she referred to her job as a yacht chef, as enabling her to accomplish her dream of cooking and travelling the world. From the above, it was evident that despite the challenges faced, participants were facing life with determination to prove themselves and to not allow dyslexia to determine their fate.

All participants revealed their goals and dreams as well as provided reasons. It is thus evident that dyslexia does not stand in the way of setting goals and working towards them.

5.7 CONCLUSION

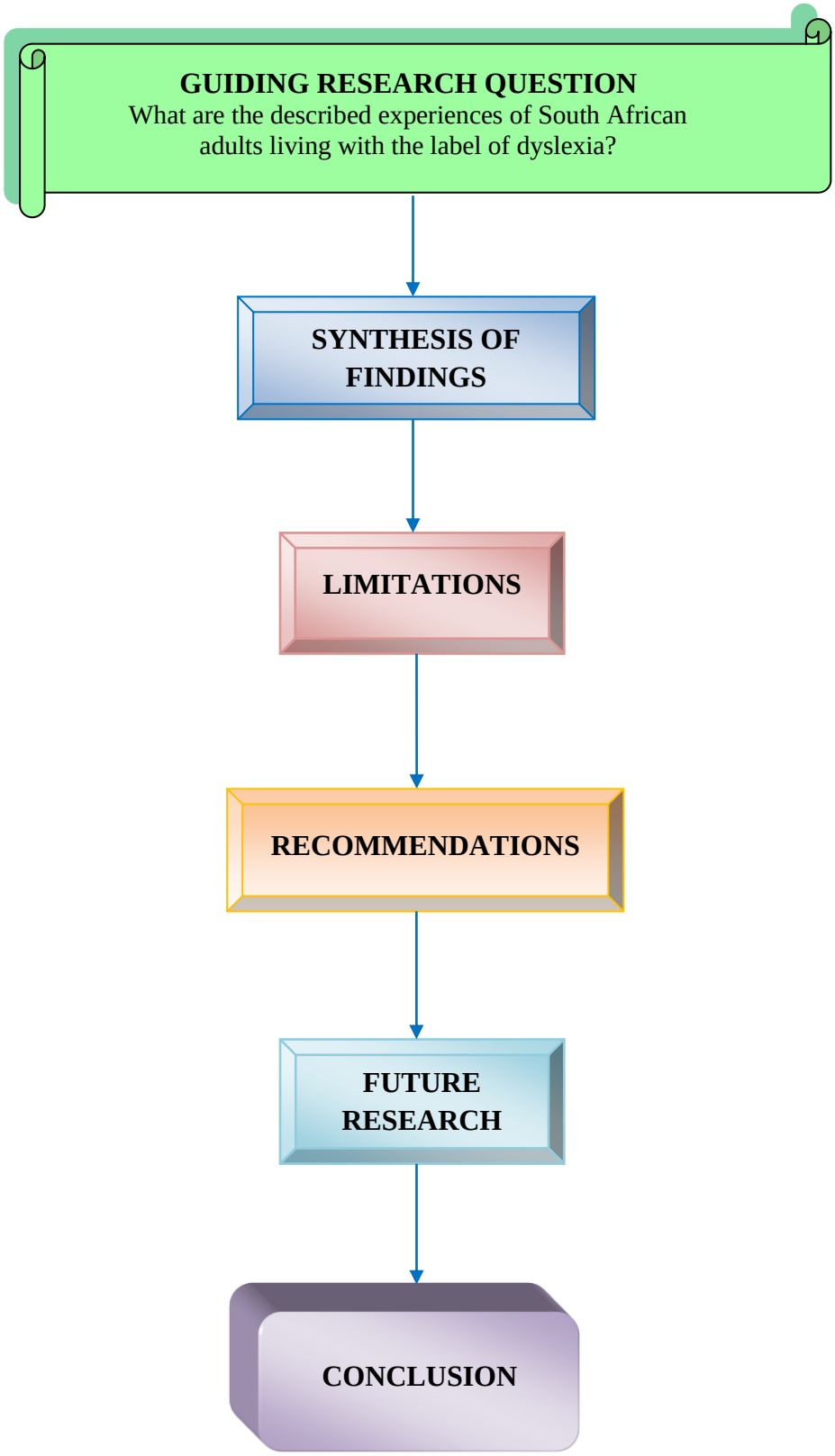
This chapter presented the analysis of the data collected using the participants' actual words, and the placement of this data into themes and sub-themes through the use of phenomenological reduction. Themes 1 to 5 provided insight into the lived experiences of adults who have been diagnosed with dyslexia and the effects of these experiences. Focus was placed on the start of each participant's dyslexia journey, this being when their challenges were first encountered. Childhood and adulthood experiences of their ecosystems, their views of the label and the effects that dyslexia has had on their needs and goals are described in the themes. The lens used to view the label of dyslexia was influenced by their lived experiences and feelings about living with dyslexia.

Chapter 6 will provide a discussion of the findings of the themes formulated in this chapter with the aim of answering the research questions. Recommendations for future research and the key limitations of this study will be provided.

CHAPTER 6

FINDINGS, CONCLUSION AND RECOMMENDATIONS

OVERVIEW OF THE CHAPTER



6.1 INTRODUCTION

Dyslexia is considered to be one of the most common learning challenges, yet it is shrouded in debate with some denying its actual existence. Indirectly entering into this debate, the researcher was motivated to discover the experiences and views of adults who were diagnosed with dyslexia and hence living with this challenge, as well as to explore their feelings about the label of dyslexia. Literature reveals that academic research providing the innate feelings of those with dyslexia as told by them is scarce and hence limited, both internationally and nationally. This study provides the intrinsic views of adults living with dyslexia and hence experiencing it first-hand. In so doing, these individuals were afforded the opportunity to make their voices heard, and not have this done for them by others.

Chapter 5 provided a comprehensive overview of the 'lived world' of adults with dyslexia, who participated in this study. These adults' subjective narratives, providing their interpretive realities, were used extensively in analysing the data, thereby leading to the formation of themes and sub-themes. Particular focus was placed on their experiences of the ecosystems that surround them, as well as on the effects and influences that these experiences have had on the attainment of their needs. Education was viewed as being central to all experiences, as the dyslexia journey of each adult commenced whilst they were learners. Furthermore, educational experiences are revealed as impacting the entire lives of these individuals, including the attainment of their needs.

In this chapter, the findings from the study in conjunction with the findings of the literature review is presented and discussed. The limitations of the study are considered and recommendations for policy and practices as well as further research are made. The chapter culminates with final conclusions being drawn.

6.2 SYNTHESIS OF FINDINGS

Findings were guided by the conceptual framework selected for this study. Data analysis produced several findings that described the lived experiences of adults who have been diagnosed with dyslexia. These findings are summarised with reference to the literature review and used to answer the main research question in 1.6, as well as the sub-research questions found in 1.6.1. Answers were obtained by focusing on the similarities and differences of the participants' experiences provided in the five themes presented in Chapter 5.

6.2.1 What is dyslexia?

The lens of adults, who are living with dyslexia and experiencing it first-hand, is used to answer this question, thereby revealing what dyslexia is and means to the participants. Whilst the existence of dyslexia is debated, criticised and doubted by some (Elliot, 2006; Elliott & Gibbs, 2008; Elliot & Grigorenko, 2014; Rice and Brooks, 2004), it is a reality for those experiencing it and hence living with this learning challenge. Findings confirm that whilst the challenges of dyslexia can be negated, dyslexia is a learning challenge that is never outgrown, and therefore remains with the individual, as seen in Table 4.1 (from diagnosis age to present age). Data further confirms that dyslexia tends to be hereditary and occurs in families (Allen, 2010; Anderson, 2011: Anderson and Meier-Hedde, 2011; Capellini, et al., 2011; Henry, 2015; Van der Leij; 2013). Five of the eight participants, as shown in Table 6.1, have parents, siblings or extended family members who have either been diagnosed with dyslexia or remain undiagnosed

Table 6.1: Family members with dyslexia

Participant	Diagnosed family members	Undiagnosed/suspected family members
Jane		Dad
Mary	Older sister and three older brothers	
Clive	Younger brother	Father and paternal grandfather
Henry	Mother and younger brother	
Kim	Older and younger brother	

It is revealed that often parents and grandparents have not been diagnosed, with the diagnosis of their child resulting in them realising the cause of their challenges and that their challenges

have a name (Grimes, 2009; Zipzer, 2007). Family members living undiagnosed and only later discovering that their challenges are caused by dyslexia, appears to be fairly common (Hanning, 2016; McLoughlin et al., 2002; Troeva, 2016).

- **The participants' dyslexia challenges**

Dyslexia is described as challenges faced with accurate and fluent word recognition as well as spelling and decoding challenges (Rose, 2009; Shaywitz et al., 2017). Whilst this is a fairly condensed description, it appears to accurately describe the main dyslexia challenges experienced by all participants in this study. Acknowledging their awareness that there are degrees of difficulty for those with dyslexia (Alexander-Passe, 2015; Goodwin & Thomson, 2012), all participants referred to the struggles that they faced, to learn how to read and write with the use of conventional teaching methods.

The participants' precise descriptions of their reading and writing challenges, aptly corresponds with the term 'word blindness' used by Kussmaul in 1877, to describe those who battled to read (Lawrence, 2009), as well as with the meaning of the word dyslexia provided in Bornman, Bornman and Rose (2017) and Burden and Burdett (2007). Like Kussmaul's patient (Selikowitz, 2012), all the participants were educated in fairly well-resourced schools and their intelligence, when looking at their adult achievements, cannot be questioned or viewed as being below normal. This further makes understanding of the challenges extremely difficult, including understanding this themselves. Further complicating this understanding is that the skill of reading and writing was achieved by their peers, with little or no effort. Despite their inabilities, participants desired to read just like their peers did and attempts made by them were often convincing. Frequently, those who listened to them reading did not realise that the actual printed words were not being read, and that reading was guided by the pictures, if available, or by memory.

Despite the challenges faced and the lack of understanding experienced, participants do not question their intelligence or see their intelligence as being inferior to that of others. The participants unabashedly refer to their intelligence where they state that they are clever and smart and know that they are not 'stupid'. They are aware that they have strengths in areas that those without dyslexia find challenging, and that these strengths are the result of their ability to think differently, as well as to them having above average visual skills. The participants

referred to their strengths with pride and gratification when providing examples of their superiority in areas where others are deficient.

Mary: *We think differently and we think creatively and we think out the box. I look at my siblings and myself who all have dyslexia, and then I look at my cousins and friends. There was a multiplication math problem where my friends used multiplication tables starting from the top like 1, 2, 3, 4.... whereas I find a whole lot of different links to get the answer. My friends would almost be like a parrot. I know my older brother is the same as me. We can say multiplication tables backwards, it's easy or we can start in the middle. We learn and think of something that has a connection in a certain way to it.*

Kim: *We* [her partner] *bought a couple of furniture pieces that come with picture instructions, so there's no words on the on the instructions. You just have to look at the picture and figure it out. I can figure out the pictures. But he can't figure out the pictures, like it's not his skill. But he also isn't the best at building. So, any time we build anything I have to do the building and he has to try and figure out the picture which means everything takes four times longer than it has to.*

Findings therefore affirm that those with dyslexia are intelligent (Hudson et al., 2007), creative (Goodwin & Thomson, 2012) and show average and above average intelligence in areas not based on reading and writing (Henry, 2015). The careers followed by the participants include being a chef, graphic designing, web page development, events management and mechanical engineering. It is evident that despite their dyslexia challenges, all participants were experiencing success in their chosen fields, which were strategically selected and based on their strengths. This success is enhanced by the support and understanding, provided to them by those in their ecosystems, commencing with family understanding and support.

- **The participants' perspective of living with dyslexia**

Findings reveal that positive experiences resulting from interactions with their ecosystems, affected the way in which the participants viewed their dyslexia and hence their feelings towards living with dyslexia. Family support as well as support from peers, spouses and significant others, have led to the majority of the participants embracing their dyslexia positively and viewing their dyslexia as a motivator that encourages them to be successful. As a result of embracing their dyslexia and knowing that it will always be a part of them, data reveals that there is awareness that their feelings of frustrations and inadequacy must be brief.

The participants are cognisant that living with continued frustrations caused by their dyslexia challenges provides dyslexia with power over them, thus allowing dyslexia to control their lives. To prevent this control, the participants are continually mindful that feelings of frustration are counterproductive, especially in view of the fact that they will always have dyslexia and are therefore unable to change this aspect. They however, yearn for their hard work to be recognised by role players especially in education as well as in the workplace and for their limitations to be understood.

Even though their dyslexia challenges often lead to them needing the assistance of others, continually having to prove themselves and to work even harder than those without dyslexia, they rise to the challenge. Working harder proves their skills to others and to themselves, as well as revealing that they are capable despite their dyslexia challenges. Therefore, the stigma faced from others and being judged as unable, made the participants fight even harder to show that they are accomplished, thereby enhancing their success. Many attributed their success to them being dyslexic and revealed that they are content to live with their dyslexia challenges, as they believe that there is value in being dyslexic.

Their perspectives of living with dyslexia are powerfully expressed with firm conviction by the participants:

- Dyslexia is not a negative thing;
- Dyslexia is my unique part of me;
- I'm ok with it – I'm not hurting anyone;
- There are so many upsides to having dyslexia – you have to focus on them and find a way to make it work for you;
- If you believe that dyslexia is a problem then you will have a problem;
- It's just an aspect that doesn't really affect me;

A powerful analogy that gives significant insight into the lives of those with dyslexia was comprehensively summed up as: *I always felt like my screen was cracked. You know like your cell phone … it still works but the screen is cracked. Broken but it's not unfixable* (Kim). In looking at this analogy, it is significant that both the negative and positives of dyslexia are conveyed; however, despite commencing the description with a negative, the description ends with a positive.

- **Reducing the secondary effects of living with dyslexia**

Notwithstanding the participants' positive embracement of their dyslexia, secondary effects emerge where concentration, self-confidence and/or self-esteem are negatively impacted (Ingesson, 2011). Therefore, it is important that dyslexia is understood and addressed by significant role players in these individuals' ecosystems, to assist with negating such secondary effects. Support from family, friends, schools, teachers, the workplace as well as the laws and policies emanating from the macrosystem, contributes positively to the lives of those with dyslexia and is therefore of vital importance for their emotional well-being (Rose, 2009).

Based on the aforementioned possible secondary and hence negative effects, an early and specific diagnosis is revealed as being imperative. Findings reveal that an early and specific diagnosis provides a reason and explanation for the challenges faced (Rose, 2009), with this understanding by all role players enhancing the success of those with dyslexia. It is important that diagnosis must be followed with a positive disclosure to the diagnosed individual. Disclosure is revealed as playing an important role in the lens used by these individuals to view their dyslexia and thereby assisting with their coping mechanisms. As dyslexia impacts on many facets of the individual life (Fawcett, 2016), non-disclosure is revealed as having a negative and hence detrimental effect on the individual.

- **Coping mechanisms**

Despite living in a technological world, dyslexia challenges complicate day-to-day living, as the ability to read and write remains a necessary skill that dominates human existence. Therefore daily, individuals with dyslexia are faced with challenges both in and out of the home, wherein the skill of reading and writing is needed. This necessitates constant anticipation of possible challenges and having mechanisms in place to overcome these. This is referred to by a participant as *learning how to crutch better as there is no cure for dyslexia* (Kim).

Therefore, various coping mechanisms are used by those with dyslexia, with such mechanisms being based on their needs and also determined by the degree of severity of their dyslexia. The use of technology, both in and out of the home, plays a major role in the lives of those with dyslexia, to assist with negating the challenges that they face when reading, writing and spelling. This includes:

- The internet, together with various software applications and computer programs that assist with writing, wherein grammar and spelling are corrected, are used frequently.

- A manual writing mechanism used by a participant is to only write in uppercase as a means to never confuse the direction in which a ‘b’ and ‘d’ are written. This was noted in the consent form that was filled in by the participant (found in the Appendices).
- Various methods to ensure that words are spelt correctly such as using ‘e’ in front of the words ‘mail and male’ to know which word refers to mail (post) and male (gender).
- Mnemonic techniques, for example, the word ‘because’ is spelt correctly by saying *“**b**uddy **e**ats **c**arrots **a**nd **U**ncle **S**am's **e**ggs... no matter how many times I write the word”* (Clive).

Even though the participants in this study eventually learned how to read and write, they have not overcome their dyslexia challenges. Therefore, their reading and writing remains at a lower level than those who do not have dyslexia, thereby confirming that the challenges of dyslexia are not outgrown or overcome. These skills remain a challenge and intense concentration is required for the execution of them, which often causes fatigue. Despite their efforts, errors still occur which sometimes can or cannot be identified and thus rectified. However, despite these challenges, those with dyslexia continue to progress and set goals for themselves.

6.2.2 Ecosystems involved in the diagnosis and disclosure of the individuals’ dyslexia

This study established that educational institutions play a minimal role in seeking an assessment and thereby obtaining a diagnosis for learners with literacy challenges, despite their awareness of the challenges faced. Schools and teachers ignored the possibility that the learners’ inabilities could be caused by a learning challenge (Holloway, 2014). Therefore, only two of the eight study participants were diagnosed as a result of being assisted by the school. A third participant was assessed at school. In later years, as an adult, this participant’s mother informed him that they were not fully informed of the results of this assessment. The parents also indicated that they did not enquire about these results as their focus was on his sibling, who had more severe learning challenges. Whilst the parents were not fully informed of the results of the assessment, it led to him attending a remedial school for two years.

Obtaining a diagnosis for the majority of the participants, was fully the responsibility of the parents who had to locate the correct professionals, mostly educational psychologists, to assist them, thus making it an expert-confirmed diagnosis (Asghar et al., 2018). This is in contrast to the diagnostic process that should commence with the teacher identifying the problem and the school referring the learner to a specialist (Troeva, 2016), or advising the parents about who

the learner can be taken to for a diagnosis. All teachers referred to in this study, as well as the schools attended by the participants, offered no advice herein. Therefore, the role of the teacher being the main referral point in the diagnostic process (Boyle, 2014), was completely lacking for all participants who were diagnosed outside of the school (privately), as a result of their parents seeking the diagnosis and thus paying for it.

Findings reveal that parents desperately sought the assistance of various professionals including occupational therapists and speech therapists, which was costly for the parents. A participant indicated that these professionals acknowledged that they were unable to assist. However, the various professionals also did not indicate who could assist with the assessment and diagnosis. Parents' persistent efforts to seek a diagnosis, despite the costs involved, were reinforced by the negative impact that the learning challenges were having on the academic achievement of their child (Bell & Tudhope, 2016). Diagnosis was also sought by the parents to provide an understanding to all role players (Hudson et al., 2007), thus revealing why the child was experiencing the challenges (Stampoltzis & Polychronopoulou, 2009).

A diagnosis of dyslexia made by educational psychologists as a result of parental efforts, occurred for six of the participants. Five diagnoses occurred whilst the participants were at school and the diagnosis for the sixth participant occurred during adulthood. A diagnosis during adulthood is revealed to be common for many adults with dyslexia (Bell, 2010) with various factors making a contribution. The cause for this participant's late diagnosis and lack of parental involvement was attributed to the parents having to concentrate on the sibling's dyslexia, which was far more severe. Disparity in the severity of dyslexia amongst siblings often occurs (Ingesson, 2011), with the bio-psycho-social-model (Figure 2.4) providing an explanation for such disparity (Armstrong & Squires, 2015). A further possible reason for these parents not seeking a diagnosis was their acceptance that the learning challenges presented were hereditary. This acceptance was based on the fact that this participant's father presents the same learning challenges.

Whilst literature and findings reveal the value of diagnosis (Rose, 2009), together with the disclosure of the diagnosis to the diagnosed individual, this study reveals that diagnosis and disclosure did not occur simultaneously for all the participants. Diagnosis and disclosure to the individuals are equally important as both have a great impact and influence on the lives of individuals with dyslexia, as a reason and explanation for the challenges and failures are

provided (Łodygowska, Chęć, & Samochowiec, 2017). Revealing the diagnosis further negates the diagnosed person's feelings that they are negatively different, or that they lack the intelligence that others have (Leitão et al., 2017). Both participants, who were diagnosed as a result of the school seeking the diagnosis, did not have their diagnosis revealed to them, as their parents made the choice to conceal it. This choice was based on their parents wanting to ensure that their children did not feel inferior and the parents feared that disclosure would cause the child to stop trying. Even though the diagnosis was sought by and obtained by the school, the school played no role in encouraging the parents to disclose the diagnosis to the child. Eventual disclosure by their mothers occurred years later, when it was evident that non-disclosure was having a negative effect on the participants. This negative effect was evident when the participants showed a lack of understanding of their challenges and questioned their intelligence. Both participants, whose diagnoses were not revealed to them, stated that eventual disclosure by their mothers, provided answers to many of their questions. Discovering their diagnoses enabled them to make sense of their challenges, which eased their frustrations. Findings in this study confirm that non-disclosure results in feelings of pain and embarrassment, whilst disclosure reassures the individual with dyslexia that they are not stupid (Ingesson, 2007).

Whilst all five diagnoses sought by the parents were immediately followed by the disclosure of the diagnosis to the individual, findings reveal that disclosures were predominately provided by the mothers of the participants, with the exception of two participants. One participant's disclosure was done by both parents, whilst the second participant's disclosure was made by the educational psychologist responsible for the diagnosis. This psychologist's disclosure and explanation of dyslexia was revealed as being of immense assistance in this participant's lens used to view her dyslexia. Positive disclosure can lead to positive reactions to the diagnosis, as it provides an understanding for the challenges as well as a name (Rose, 2009). Unlike Ingesson (2011), where the acceptance of the diagnosis was not unanimous, all participants in this study accepted the diagnoses and hence the disclosure, as this was affirmation of their intelligence and abilities. Knowing that they were dyslexic provided reasons and hence understanding of why they were experiencing their reading, writing and spelling challenges.

6.2.3 Family, education and peer experiences prior to being diagnosed and labelled

Data in this study reveal that both the parents and the participants' experiences prior to obtaining the diagnosis were fraught with frustration for the majority of the parents and the participants. Parental desperation to seek assistance for their child is revealed by three of the five participants who were diagnosed as a result of parental efforts made to obtain the diagnosis. The remaining two parents did not experience this because:

- The teacher assisted the parents by disclosing the name of the educational psychologist who could do the assessment and diagnosis; and
- The parents of the remaining participant were prepared for her possible diagnosis as a result of having older siblings who had already been diagnosed. As the parents knew who could provide the diagnosis, they did not experience the frustrations of the other parents. This lack of frustration was also as a result of the child being home schooled and not having to face the pressures that mainstream and independent schools placed on the participants and parents.

Whilst the school played a minimal role in the actual diagnosis of three participants, both parents and participants continuously experienced negative feedback from the school. The actions of the school and teachers placed undue stress on both the parents and the learners. Focus appeared to be solely directed at the learners' inabilities resulting in the failure of the teachers to realise the efforts and strengths of these learners (Fairbanks, 1992). Frustrations imposed by the school and teachers, on the parents and the learners included:

- Parents and family members trying to assist the learner with school work, and this often resulted in undue stress for those assisting as well as for the learner;
- Continually being informed by the school and teachers that there was something 'wrong' with the learner;
- Parents being informed that the learner was not working to the best of his/her ability;
- Learners were labelled as lazy and not trying; and
- The school apportioning blame to the parents for the learner's challenges.

Further to these frustrations, a parent endured her child receiving corporal punishment that was metered out by the principal on a weekly basis, because of the dyslexia challenges presented. This however, stopped once a diagnosis was made and the parent requested that the child be moved to a remedial school. It is therefore evident that the role played by the school and teachers towards the participants and their parents was predominantly negative, with the

exception of the participant who was home schooled. Participants in both the public and independent schools revealed the constant negativity, lack of care, lack of understanding and a lack of compassion that was shown to them. As a result, the school environment was revealed as unpleasant, as one that presented insurmountable challenges (Zipzer, 2007), where the learners' with dyslexia's efforts were not considered. Therefore, the challenges to turn the negative experiences of the participants into positive experiences were solely the responsibility of the parents.

Parental determination to assist their children to the best of their ability was revealed in most interviews. However, the parents' decisions herein did not have the desired result. Three sets of parents chose the schools that their children should attend, with this choice not being of value for the learner. New schools provided no respite in that these participants remained unhappy at school and still battled academically. Continuous change resulted in a participant who was educated solely in mainstream education (Shana) to leave school at the end of Grade 10. This was caused by her having attended all the schools that were close to where she lived and not finding a school where the environment was positive and not negative towards her dyslexia.

6.2.4 Family, education, peer and society experiences subsequent to being diagnosed and labelled with dyslexia

Family experiences showed very little change after the diagnoses of the participants as compared to prior to diagnosis. Education continued to be a frustrating and stressful experience for both the participants and their parents. Schools remained inflexible and did not provide for the participants' learning needs, resulting in them as learners being angry, unhappy and frustrated (Chu et al., 2011; Wearmouth, 2004). Emotional and academic support and encouragement, as well as assistance with school work, remained the responsibility of the parents and their siblings, with little or no help from the teachers. Such support was critical for the overall well-being of the participants (Gyarmathy, 2011; Nalavany & Carawan, 2012) and has greatly contributed to the participants coping academically, despite their challenges. The participants' family experiences have also played a major role in contributing to their success as adults.

However, the extent of parental involvement and support post diagnosis, were determined by circumstances where the degree of severity of the dyslexia, the time available to parents, as well as parents having to focus on siblings with greater challenges. Continued assistance provided by parents was a necessity for the majority of the participants. This was the result of the education institutions' failure to acknowledge the diagnosis, make the needed accommodations and recognise that the challenges presented by the learners were caused by their dyslexia. This resulted in some parents continually seeking schools that would assist their child and a school in which the child would be happy.

Findings revealed that only two schools made the necessary accommodations for the diagnosed participant and both were based on a home-schooling system. Public and independent schools attended by the participants in this study, are revealed as denying the learner the necessary accommodations required by those with dyslexia, such as extra time given in tests and examinations, or a scribe to assist with the reading of the examination questions (DoE, 2014). This attests to the inflexibility of the schools attended by the participants of this study, towards those with dyslexia, with this inflexibility validated in Alexander-Passe (2015b). Therefore, ensuring that the educational needs of learners with dyslexia are met wherein they receive the correct intervention and assistance, was predominantly the responsibility of the family.

Unlike Nugent (2008), special schools and remedial schools in this study are disclosed as having no value for those with dyslexia as their specific challenges were not addressed. Hence teachings in these schools were not directed at assisting them with their challenges. It was revealed by the participants that all learners in remedial schools, irrespective of their learning challenges, were taught using the same methods. Participants who attended remedial schools felt that their education was negatively affected, as the pace in these schools is much slower than in mainstream schools. As the intellect of those with dyslexia is not negatively affected by their dyslexia, the slow pace caused much frustration for the three participants who were placed in these schools. Therefore participants, who attended remedial schools, are of the view that the system was responsible for holding them back from what they could have achieved.

All three participants who attended a remedial school for two years, indicated that returning to mainstream education, was extremely challenging because of the lag caused by the slower pace in remedial schools. On their return to mainstream education, they were of the view that they carried the label of having attended a remedial school. Mainstream schools and teachers placed

them in a category of being a slow learner, hence they were labelled. Participants often referred to their intellect and therefore not fitting into special and remedial schools, where many of the learners are not on the same level of intelligence. Remedial schools are therefore revealed by the participants, as not conducive to the needs of those with dyslexia.

After their two-year placement in special schools, learners with dyslexia continued to experience incorrect school placement. A participant (Walter) was placed in a special school (technical school), after completing two years in a remedial school, with his parents being guided to make this choice by persons in the education system. A teacher in this school informed him that he should have been in mainstream education and did not belong in the technical school because of his intellect. Unfortunately, this placement negatively affected his education as he does not have a matric certificate, because whilst he attended the special school, it ended at Grade 10 level. This validates that learners with dyslexia appear to be indirectly categorised and hence labelled as slow learners and not being able to cope in mainstream education. Could the use of their dyslexia label, the correct label for them, negate these experiences and enhance an understanding of their learning challenges for all role players?

Negative feedback from the majority of the teachers and not being understood or assisted by teachers is a common experience shared by all, with the exception the home-schooled participant. Reflecting on their teacher experiences throughout their schooling, a maximum of two teachers were named by each participant, regarding assistance provided, understanding shown, concessions made and an acknowledgement of their dyslexia challenges. Therefore, the lack of assistance and understanding shown towards their dyslexia challenges resulted in unhappy schooling experiences. Criticisms of their academic efforts were rife as a result of their efforts not being recognised. Some participants believed that their diagnosis was viewed by teachers as an excuse for laziness, inabilities, and them not trying. This view is validated in the experience of a participant, who despite her diagnosis being known, was sent for corporal punishment as a result of her poor test results.

Humiliation inflicted by teachers was a common experience. Even though teachers were informed that reading aloud is embarrassing and a traumatic experience for those with dyslexia, some teachers persisted with asking them to do so. Such uncaring teacher reactions are implied to be deliberate, thereby inciting feelings of frustration, anger, hurt, despair, inadequacy and defeat within the participants. Continued negative school and teacher experiences led to the

majority of participants questioning themselves and their inabilities (Wearmouth, 2004). The actions of these teachers, contributed to negative peer experiences, as the learner was ridiculed by their peers for their inabilities, which were highlighted by the teachers. Therefore, the school and teachers are viewed as playing an important role in peer reactions and treatment of learners with dyslexia.

In this study, data reveal that a diagnosis of dyslexia does not alter peer experiences during childhood and adolescence. Whilst some experienced rejection or being isolated by their peers, bullying was minimal. Negative experiences included peers being judgemental in their words and actions or ridiculing them for their challenges and inabilities. Some peers viewed the literacy challenges of those with dyslexia as being equated with a lack of intelligence, thereby resulting in negative peer experiences. Findings reveal that the personality and temperament of those with dyslexia play a role in the responses and hence reactions given to such peer experiences. Three of the participants were negatively affected by their peer treatment resulting in them feeling friendless and therefore outcasts. These participants yearned to be accepted by their peers and not judged because of their dyslexia.

The actions by all in education towards dyslexia that has been revealed could be based on ignorance about this learning challenge. This could be attributed to the education department's stance towards dyslexia (Anderson & Meier-Hedde, 2011), as well as the failure of the teacher training education system to address dyslexia (Williams & Lynch, 2010). Teachers appear to be ignorant or ill-informed about dyslexia, as well as how to teach those who are dyslexic (Earey, 2013). My limited finding as a researcher is that a few of the teachers that I have spoken to about this study, did not know about dyslexia. This finding is validated by a retired teacher who taught remedial education for many years asking me to explain dyslexia to her.

6.2.5 Impact of dyslexia on adulthood

Data in this study reveal that adults with dyslexia are faced with numerous day-to-day challenges that require them to anticipate these challenges, and therefore be prepared by having plans in place to overcome them. Therefore, living with dyslexia as an adult necessitates having good coping skills, acceptance of their dyslexia and being able to disclose it to others when necessary. Findings show that achieving the above, contributes to their quality of adult life.

Adult dyslexia challenges are faced in tertiary education institutions, the work place, filling in forms, driving learner licence tests, during social activities such as reading restaurant menus, and general day-to-day living such as shopping which requires the reading of lists and labels. All participants revealed that they have good and bad days with regards to their reading and writing challenges. On good days, reading and writing is less of a challenge, whilst on bad days, the execution of these skills is extremely challenging (Patton, 2015). It is therefore essential that support and assistance is provided by their surrounding systems.

Participants in conjugal families and in adult relationships indicate that their spouses and partners fully accept and assist them where possible. No negative family experiences are therefore revealed; however, it is felt that spouses lack a full understanding of the dyslexia challenges experienced. Literacy skills are achieved almost habitually by those who do not have dyslexia, therefore the inability herein is hard to understand for both those with and without dyslexia. Spouses have however, also learnt to anticipate possible challenges that their partner might experience in certain situations and they also have mechanisms in place of how they can assist. For example, a shopping list with words is accompanied with pictures or the colours of the particular flavour or brand to be purchased, in cases where there are varieties. A further example is accompanying them to places where forms have to be filled in so as to provide assistance, or taking the role of filling in forms needed when travelling to another country.

Whilst all public and independent school participants did not receive the needed dyslexia concessions as learners, they however, acknowledged that tertiary institutions attended by them as adults provided them with their needed concessions. Findings reveal that despite the Department of Basic Education and the Department of Higher Education falling under the umbrella of the South African Department of Education (Figure 2.1), their provision of the needed dyslexia concessions differed greatly. The Department of Basic Education, which controls primary and secondary education institutions, failed with the provision of dyslexia concessions to those requiring it. This occurred despite the KZN Circular No 31 of 2014 that stipulates that if proof of dyslexia is provided by way of a report from a professional, the history of the case is given as well as the reading and writing rate is indicated, a selection from the following concessions can be made:

- Extra-time;
- Adapted Question Paper;
- Scribe/reader/assistant;
- Computer/typewriter;
- Spelling and/or handwriting flag;
- Oral assessment (internal assessment tasks only);
- Exemption from certain compulsory subject offering (DoE, 2014, p.5)

Such concessions were however, provided by the Department of Higher Education and Training under which universities and post-secondary education fall. South African government departments such as the Department of Home Affairs, responsible for the issue of Identity Documents and Passports, as well as the Department of Transport responsible for issuing driving learner licences provided the needed concessions to those with dyslexia. These departments have measures in place where those with dyslexia, who provide proof of their diagnosis, are assisted with the filling in of forms and with the driving learner licence, a scribe is provided who reads the questions and oral answers are accepted.

Participants with workplace experience described the mechanisms that they use to overcome their dyslexia workplace challenges. Disclosure of dyslexia in the workplace appears to result in fewer negative experiences shown towards the challenges sometimes exhibited. With disclosure, even though employers and colleagues in the workplace lack a full understanding of dyslexia, they appear to be less judgemental of the challenges and errors presented by those with dyslexia. Findings show that non-disclosure can result in stigmatisation, ridicule, humiliation and constant belittlement. The choice made not to disclose their dyslexia can be based on the stigma and ignorance surrounding dyslexia, as this could lead to negative labels being used (Alexander-Passe, 2015a). This was experienced by a participant who did not disclose her diagnosis, resulting in her work always being seen as below average and therefore always checked for errors. Eventual disclosure did not change this negativity, but resulted in exploitation of this participant for the benefit of the firm's status by having a disabled worker. Therefore, it is evident that societal understanding of dyslexia plays a large role in contributing to positive experiences of adults with dyslexia.

6.2.6 Views of the label of dyslexia

Literature reveals that the views of adults with dyslexia, towards the label of dyslexia are scant and limited; hence the findings herein contribute to increasing this knowledge base. Views regarding the label of dyslexia have mainly been provided by secondary persons (those without dyslexia), with these views being implemented by education and society at large. Literature reveals that, based on the views of others, labelling should not occur as labels are viewed as negative instruments. However, this view is not substantiated in the findings of this study. Labels in life are viewed as inevitable, therefore it is imperative that control is exerted where the correct labels are used and encouraged; however, the label must be seen as describing just an aspect of the individual.

All participants were articulate in providing their views of the label of dyslexia (Hudson et al., 2007). Findings reveal that the label does not have negative connotations for the majority of the participants, as they are of the view that it does not refer to something that is adverse. Such positivity results from being content with the diagnosis, living with the challenges of dyslexia (Leloup & Sprenger-Charolles, 2011) and not seeing dyslexia as negative. Most participants stated that the label should be used by those in their surrounding systems and not be avoided, as the use of labels is inevitable. Using the dyslexia label and not avoiding it, will reduce the stigma surrounding the label as well as negate the negative labels that are used in its place. Further, recognising and using the dyslexia label could result in this label no longer being viewed as something that is negative. However, to achieve this, societal understanding of dyslexia is imperative. Society has to be educated about dyslexia which will increase knowledge and understanding (Macdonald, 2009). This could reduce the stigma associated with the label and enable society and all in their surrounding systems to realise that the label refers to a small aspect of the individual and does not encompass their abilities completely. Therefore, present day negativity surrounding the dyslexia label might be attributed to societal ignorance of dyslexia, as well as the failure of role player to use the label.

Findings reveal unanimous consensus regarding the use of the label of dyslexia in education, as it indicates that those with dyslexia are not academically challenged in all areas and therefore unintelligent. The label is viewed as a valuable mechanism that can be used to explain the challenges of those with dyslexia and designate the areas in which they need assistance, thereby not diminishing their capabilities and skills in other areas. The label can therefore provide an understanding to others about the specific challenges of those with dyslexia and why they

experience these challenges. Avoidance of the label results in the specific challenges of the individual not being understood and therefore addressed. Without the label, their intelligence is viewed negatively and they do not receive the appropriate academic intervention for their specific needs. The unanimous views of the participants are that frequent use of the label of dyslexia will not only alleviate the negativity presently surrounding it, but it will no longer be viewed as a label, but as a fact.

6.2.7 Effects of the label of dyslexia on the attainment of needs.

The needs of the participants in this study, as identified in Maslow's Hierarchy of Needs, that can be affected as a result of dyslexia experiences and challenges, are the psychological and self-fulfilment needs. As belonging and love needs have been discussed in the findings provided in the previous questions of this study, esteem needs that can impact on self-actualisation are focused on, to answer the question asked herein. The participants' self-confidence, self-esteem and goals were explored to reveal the effects that the diagnosis and label of dyslexia has had on the attainment of these needs.

Diagnosis and disclosure are revealed to play an important role in both self-confidence and self-esteem. Early diagnosis not only provides a more adequate understanding to those with dyslexia but is also related to them having higher competency perceptions of themselves (Battistutta, Commissaire & Steffgen, 2018). Acceptance of the diagnosis, the explanation and timing of the diagnosis, the attitudes of those closest to the diagnosed individual and the ease of disclosure, plays a role in the attainment of these needs. Appropriate interventions lead to acceptance and achievement, thus impacting positively on self-confidence, as well as on the attainment of needs (Stringer et al., 2011).

Findings reveal that the participants' self-confidence has not been negatively affected by their dyslexia, with the exception of one participant (Jane). This lack of self-confidence can be attributed to late diagnosis, the frustrations experienced in trying to obtain the diagnosis as well as the negative experiences from those in her systems, with the exception of her parents. In particular, negative school and teacher experiences appear to have indelibly negative effects on her self-confidence, which was evident in her demeanour and in the answers provided. Findings reveal that disclosure of the diagnosis to the participants, provided an understanding to them, thereby reducing inner negative feelings and impacting positively on self-confidence (McLoughlin et al., 2002). Even though the majority of the participants revealed that their self-

confidence was not negatively impacted by their dyslexia, this finding differed with their self-esteem.

Data reveal that the effect of dyslexia on the self-esteem of adults is influenced by the mindset of the individual as well as support from those in their ecosystems. Whilst two of the participants have never allowed their dyslexia to negatively affect their self-esteem, this did not occur for the majority of the participants. As learners, six of the participants revealed that they had a low self-esteem. However, maturity, coping mechanisms and realisation of self-worth, have played a role in negating these adverse effects for five of the participants. The remaining participant (Kim) is battling to achieve this need, despite her academic achievements. A factor contributing to this lack of self-esteem is that her diagnosis was hidden from her until she was at the end of her schooling. This validates that an early diagnosis, with disclosure and appropriate interventions can improve the self-esteem of the individual (McNulty, 2003). Failure to understand her challenges as well as her negative experiences of those in her ecosystems have left scars that remain with her. Failure in her attempts to erase and overcome these negative experiences is impacting negatively on her self-esteem. Whilst her dyslexia experiences have increased her determination to succeed, these experiences have created insecurities that cause her to doubt her worth and value, especially in her relationships with others.

However, despite dyslexia having a negative effect on the achievement of self-esteem for the majority of the participants when they were younger, data in this study reveal that with the exception of one participant (Stacey), this negative effect is not exhibited in their goals. Seven participants, irrespective of their ages, revealed their goals and this was done with much enthusiasm. Goals disclosed are however, guided by their strengths, what they enjoy doing and in some, the desire to assist others.

Careful consideration has been given to their inadequacies caused by their dyslexia challenges as these could impede the achievement of goals. Goals are based on their computer skills, drawing, design, creativity, mechanics, entrepreneurship and verbal communication (Bornman & Rose, 2017; Goodwin & Thomson, 2012; Hickman & Brens, 2014). Whilst it cannot be stated that self-actualisation has been reached, data reveal that all participants are actively involved in achieving their goals and working towards self-actualisation. Therefore, findings show that dyslexia will not prevent the participants in this study from achieving self-

actualisation as they are presently surrounded by a strong and positive mesosystem and exosystem.

6.3 LIMITATIONS

Whilst this study has provided descriptive insight into the lived experiences of adults with dyslexia, limitations exist which could impact on the research findings. Limitations regarding generalisability and bias were noted from the onset of the study and were used as a guide to direct the selection of the research method and research design. Acknowledging that the sample group was small, and that it could be suggested that the participants were not a good representation of the population, qualitative research was conducted. The aim of this type of research is not to generalise but to provide descriptions of the explored phenomenon, and to provide interpretations of the conveyed experiences. Bias was negated through the use of phenomenology which enabled the bracketing of bias, which was noted through reflection and using the actual words of the participants to make the findings. However, limitations existed over which the researcher had limited control.

Limitations were imposed on the researcher with the selection of the research participants. As the researcher did not have direct access to the names of adults who have been diagnosed with dyslexia, there was dependency on a third party (the director of a dyslexia organisation) to provide the names of possible participants. Assistance from this person ensured that the research criteria of the study were adhered to, with the main criteria for the feasibility of this study being that a formal diagnosis of dyslexia had occurred. Formal identification was of paramount importance to ensure that the participants' challenges were caused by dyslexia and not by other learning challenges. Therefore, the names of the eight research participants were provided by the said person.

As a result, the sample group was restricted to persons belonging to this organisation. Based on this, diversity related to the types of schools attended was not achieved as all were from middle-income backgrounds. The sample group comprised of persons whose basic needs were met and with all having attended fairly well-resourced schools that had previously been controlled (pre-1994) by the white education department, as discussed in 2.2.1. The monetary allocations for schools run by the white education department were much higher than for the other three race groups found in SA. Therefore, adults with dyslexia, who attended schools that were controlled by the Coloured, Indian and Black education departments pre-1994 had scant

or fewer resources, were not included in this study. Diversity in this study was further restricted in that participants were all educated in a specific geographical setting namely KwaZulu-Natal, which is one of nine provinces in SA. Therefore, future research should include participants who attended schools formerly run by the Coloured, Indian and Black education departments, with such schools being in various geographical locations.

Dyslexia is a clinical label that refers to a learning challenge that is varied in terms of severity and has a cluster of symptoms, therefore resulting in persons experiencing their dyslexia challenges differently. All participants, whilst differing in degrees of severity, revealed that their main dyslexia challenges revolved around reading, writing and spelling. Therefore, the spectrum of dyslexia challenges associated with dyslexia was confined. However, despite these limitations, this study has provided new insight into the lived experiences of adults with dyslexia; particularly as such insight is scant and limited in academic literature.

6.4 RECOMMENDATIONS TO ASSIST THOSE WITH DYSLEXIA

Recommendations are guided by the selected frameworks of the study. Focus is directed to the ecosystems of individuals with dyslexia, and their contribution needed to improve the experiences of those with dyslexia and assist them in acquiring the needs identified by Maslow, possibly leading to self-actualisation. The role of policy is identified as setting the foundation for positive change.

- **Policy**

Policies should be in place focusing on the diagnosing of those with dyslexia. Such laws and policies should provide guidelines indicating:

i. Who can make the diagnoses;
ii. The diagnostic procedure/s to be followed;
iii. The training of educators to teach learners with dyslexia;
iv. The value of early intervention;
v. The provision of accommodations that might be needed;
vi. The importance of diagnosis and disclosure.

The following recommendations are made by this study regarding diagnoses and disclosure:

- Avoid late diagnosis and delayed disclosure as this negatively impacts these individuals and causes them to doubt their intelligence;

- Early diagnosis or identification is important as this provides an understanding to parents, teachers and the school;
- Positive disclosure of the diagnosis to those with dyslexia is imperative as such disclosure provides them with a reason and an understanding of why they are experiencing their challenges;
- Positive disclosure results in these individuals having a higher competency perception of themselves.

- **Education**

Education is highlighted as playing a major role in the lives of those with dyslexia and has impacted on their adult experiences. To improve the schooling experiences of those with dyslexia:

- All teachers and school administrators should be provided with dyslexia training programmes to increase their knowledge about dyslexia.
- Schools should be more accommodating towards learners with dyslexia and provide for their concessions.
- Schools must encourage learner happiness by providing positive school and educator experiences for those with dyslexia.
- The correct school placement for those with dyslexia is essential to ensure their success.
- Schools must acknowledge that the literacy challenges faced by some learners could be caused by them being dyslexic.
- Schools must provide appropriate interventions, support and advice to those with dyslexia.
- Schools should network with educational psychologists so that they are able to advise and assist parents in obtaining a diagnosis/assessment for their child.
- Schools should work with dyslexia organisations to learn the skills of teaching those with dyslexia how to read and write.
- Educator awareness and knowledge about dyslexia in the classroom is imperative for:
  a) Teachers being more accommodating and understanding of the learning and emotional needs of learners with dyslexia;
  b) Providing pedagogical aid to these learners with the aim of motivating them academically;
  c) Enabling them to identify the behaviours and traits caused by dyslexia;

d) Enhancing their understanding and encouraging them to show compassion to the challenges of those with dyslexia;
e) Acknowledging the efforts made by those with dyslexia, and looking beyond the work produced;
f) Negating their negative treatment and demeanour towards learners with dyslexia;
g) Assisting parents by providing them with information about dyslexia and thereby reducing parenting stress associated with having a child who is dyslexic;
h) Improving peer knowledge about dyslexia and assisting them in understanding dyslexia better by explaining that various learning challenges exist of which dyslexia is one.

- Learners with dyslexia must not be placed in special schools unless they receive specific and hence targeted intervention to negate their dyslexia challenges.
- The Education Department should ensure that schools have the means and that they provide learners with dyslexia with their needed concessions.

- **People**

People and hence society, impact greatly on the lived experiences of those with dyslexia, with many indicating negative people experiences. To improve the societal experiences of those with dyslexia and to negate the stigma associated with dyslexia, the following recommendations are made:

- Societal knowledge and awareness about dyslexia need to be increased, so as to reduce the ignorance currently surrounding this learning challenge and the stigma associated with dyslexia;
- Such awareness and knowledge will enlighten all role players to the challenges faced by those with dyslexia, as well as to their possible strengths and abilities;
- Societal knowledge can result in better treatment and opportunities for those with dyslexia; and
- Workplace policies needs to be in place for the interviewing, preliminary testing used during the interview process and employment of those with dyslexia.

- **Label of dyslexia**

Recommendations are made regarding the label of dyslexia, as the use of this label or the failure to use the label and hence recognise dyslexia, impacts on the experiences and needs of those with dyslexia. These recommendations include that:

- The dyslexia label should be used and not avoided;
- The dyslexia label specifies the challenges faced by those with dyslexia, thereby revealing that they are not unintelligent;
- Avoidance of the label results in the specific challenges of those with dyslexia not being understood and addressed;
- Use of the label will reduce the stigma associated with it; however, positive use of the label is dependent on societal education in dyslexia;
- Increased knowledge and understanding from all role players will result in all being educated about the label of dyslexia;
- Use of the label should occur; however, it is important that the label is fully understood and that it refers to a small aspect of the individual;

It must however, be noted that recommendations made can only be implemented if the existence of dyslexia is acknowledged by all in the surrounding ecosystems of these individuals. Denial of dyslexia, and hence the existence of the challenges faced by individuals with dyslexia, impedes negatively on the lives of individuals with this learning challenge.

6.5 FUTURE RESEARCH

The use of the voice of those with dyslexia to discover their experiences of dyslexia and attitudes towards the label of dyslexia is limited in academic research. Recommendations for future research to increase insight herein and add longitude are:

- A replication of this study with a more diverse sample group will provide greater insight into the experiences and views of those with dyslexia. Diversity in the sample group includes participants from various provinces, various cultural groups and varied income groups or backgrounds.
- Studies that include the voice of learners with dyslexia who are educated at independent school and various public schools.
- Research that explores the attitudes of schools towards learners with dyslexia, and teacher knowledge and perceptions of dyslexia as well as their attitudes and management of learners with dyslexia.
- An exploration using the voice of teachers who are faced with teaching learners with dyslexia;

- Further studies in which parents, families, spouses/partners and peers are interviewed, to determine their knowledge of dyslexia as well as their perceptions, views, attitudes and experiences related to persons with dyslexia.
- Research that includes the voice of persons in various dyslexia associations in South Africa, as a means to provide a fuller and hence richer description of the phenomenon.
- Research into learner support programmes that assist the academic and emotional needs of learners with dyslexia.
- Research into the official position of government and the education department towards dyslexia.

6.6 CONCLUSION

Literacy skills are central to education and human existence; therefore, competency herein is of utmost importance. Whilst individuals with dyslexia find these skills challenging, they can be overcome if their specific learning needs are met through the provision of appropriate intervention. The SIAS policy (DoE, 2014) acknowledges that additional support may be required by some learners as a result of them experiencing barriers to education, with learning challenges and hence dyslexia being named as a barrier. This policy specifically states that such additional support must be appropriate for the needs of the learner. However, appropriate intervention directed towards the specific learning challenges of those with dyslexia is revealed to be completely lacking. This occurs despite the instrumental role played by education, in assisting all to achieve their personal goals, and to become meaningful and contributory members of society. Therefore, positive educational experiences are minimal or non-existent for those with dyslexia, with various factors contributing to this.

The aim to have inclusivity and uniformity has swept aside the rational and experiential reality existing on the ground that learners differ in ability. Therefore, those with additional learning needs cannot be taught using the same teaching strategies and methods. Whilst it may be politically correct to place learners with various learning challenges together in one class where they are taught using the same methods, this serves only to ensure an even bigger differentiation of the outcome of the school experience. Emphasis is currently placed on inclusivity and not discriminating against these learners but on protecting them, with this resulting in them not being labelled as dyslexic. However, such protection is actually not provided when addressing their specific educational needs.

Schools are not acknowledging dyslexia, and appear to know very little about this learning challenge to the detriment of learners with dyslexia. Acknowledging dyslexia and the challenges faced by those with dyslexia is of utmost importance to enable positive educational experiences that enhance the academic and socio-emotional well-being of such individuals. Failure herein forces these individuals to live in a world in which the existence of their challenges is denied, with this impacting on their adult life. Individuals with dyslexia yearn to be accepted, to be viewed as having strengths and talents and not judged solely on their inabilities and hence their dyslexia challenges. This can occur if all in education and society become knowledgeable about dyslexia, as this will decrease the stigma and ignorance presently surrounding it.

The power of education and knowledge is evident in the 21st century where certain labels both in and out of education are now used positively, yet in the past they were considered derogatory and surrounded by stigma. Therefore, society through education and knowledge determines the acceptability of a label. The choice made by secondary persons to not label dyslexia appears to be detrimental for the well-being of those with this learning challenge. The perceived perception that labelling is negative appears to be detrimental to the outcome of those protected by not being labelled. Despite labelling being viewed as negative, it does occur in education and is not completely evaded, as the choice is made to use the term that some learners have additional learning needs. This term is a label. Not specifying what their specific needs are, is an injustice to them, as those with dyslexia are articulate, intelligent and sometimes also gifted (Kokot, 2005; Mortimore 2003). This is clearly obvious in the eloquence of the feelings provided below:

Clive: *If you're not dyslexic what are you? Am I stupid.....? How do you not label it?*

Mary: *Having additional support needs makes you sound that you're not smart. Or that you are not smart enough to be the same as the other kids and make it work. In the case where it's just dyslexia, you know you have it, but you are still able to learn in a special way to get help from it.*

Failure to use the label of dyslexia is failing the dignity and rights of these individuals to targeted intervention, and impeding negatively on other's views of their intelligence and skills. This is not only robbing the individual in their personal capacity but is also impacting

negatively on society, wherein society is not benefiting fully from the skills of those with dyslexia. The present situation and attitudes of those in education wherein learners with dyslexia are not receiving targeted intervention is an extrinsic barrier that needs to be removed. Labelling is only bad when the term is associated with negativity and failure; however, many with individuals with dyslexia have already proved internationally that there is no rational need to bury it. The conclusion to this study is aptly provided by the words of Henry, an adult with dyslexia:

The label exists no matter what, we've got to find a way of making it into something that's a lot more difficult to use in a negative sense. And I just think it's one of those things where you want to control what it is, versus someone else putting it in a negative light.

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Appendix A- Research Ethics Clearance Certificate

UNISA

UNISA COLLEGE OF EDUCATION ETHICS REVIEW COMMITTEE

Date: 2018/10/17

Ref: **2018/10/17/4648404/12/MC**
Name: Mrs. GA Hoskins
Student: 4648404

Dear Mrs Hoskins

Decision: Ethics Approval from 2018/10/17 to 2023/10/17

Researcher(s): Name: Mrs GA Hoskins
E-mail address: ga.hoskins@gmail.com
Telephone: +27 83 798 2324

Supervisor(s): Name: Dr H. Olivier
E-mail address: olivih@unisa.ac.za
Telephone: +27 12 429 6753

Title of research:

To label or not to label: The reported experiences of South African adults diagnosed with Dyslexia

Qualification: PhD in Psychology of Education

Thank you for the application for research ethics clearance by the UNISA College of Education Ethics Review Committee for the above mentioned research. Ethics approval is granted for the period 2018/10/17 to 2023/10/17.

*The **low risk** application was reviewed by the Ethics Review Committee on 2018/10/17 in compliance with the UNISA Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.*

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.

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Appendix B- Letter to Dyslexia Association Requesting Contact Details of Potential Participants

The Dyslexia Association

Dear Ms ……

My name is GERALDINE HOSKINS and I am a qualified teacher who has taught in a primary school for 19 years. I am doing research towards a PhD (Doctor of Philosophy) at the University of South Africa, under the supervision of Dr H. Olivier, a Senior Lecturer in the Department of Psychology of Education. My study has received written approval from the Research Ethics Review Committee of the University of South Africa (UNISA). A copy of this approval letter can be obtained from me if you so wish. The title of my thesis is:

LIVING WITH THE LABEL OF DYSLEXIA

After following the required ethical procedure outlined below, we humbly request you to kindly provide us with the names of volunteers/possible participants who:

- Have a formal diagnosis of dyslexia done by a professional who is qualified to make the diagnosis;
- Diagnosed whilst in school, in tertiary education or even as adults in the workplace;
- Are between the ages of 18 and 40;
- Can communicate in English;

Attached to this letter are:

1. an information letter about my study (Appendix C) which can be given to persons whom you approach as being possible volunteers; and
2. a consent form (Appendix D) which must be signed by persons who agree to you providing me with their names and contact details.

This study is expected to collect information that could assist others, especially persons in education, in the workplace and in society, to gain an understanding of what it is like to live

with the label of dyslexia using the experiences of those who have been diagnosed with it. Much of what is known has been told by persons who do not have dyslexia, and very little opportunity to describe their experiences, has been given to persons who have been diagnosed with dyslexia. The results of this study will provide a description of what it is like to live with the label of dyslexia and possibly provide others with an understanding of these experiences. I am of the view that adults satisfying the above-mentioned criteria, are able to contribute immensely to this study because of their wider and longer life experiences. I am hoping to have at least 10 participants both male and female. Complying with the ethical requirements of the study, no payments will be made to those who are participating.

Individual and therefore private semi-structured interviews will be conducted which will enable the participant to describe their experiences of the label of dyslexia. Permission will be sought from each participant for an audio recording to be made of the interviews, to ensure that the interview will be accurately captured. The questions asked will focus on all systems including the self, family, school, teacher and peer experiences before and after diagnosis, reactions to the diagnosis and experiences after diagnosis. Questions will also include tertiary education experiences and workplace experiences (if applicable) as well as social experiences as an adult. Interviews will take approximately 90 minutes at a venue and time that is convenient for the participant. I will provide each participant with a notebook wherein information recalled after the interview can be recorded. Follow-up interviews might be needed to clarify what was discussed in the interview or if further information is needed by me.

Participating in this study is voluntary and those approached to provide their contact details and possibly participate are under no obligation to consent to participation. If they do decide to take part, participants will be given an information sheet (Appendix E) similar to the one in Appendix C to keep. They will be asked to sign a written consent form agreeing to participate however; participants will be free to withdraw at any time and without giving a reason.

Participation in this study might be for the benefit of providing others with an understanding of the experiences of those who have been diagnosed with dyslexia and more especially for learners with dyslexia. This study will also provide participants with the opportunity of making their voices heard regarding what it is like to live with the label of dyslexia. Academic research into what it is like living with the label of dyslexia and views about this label using the voice of those who are diagnosed is limited. The aim of this study is to contribute to the body of

knowledge about dyslexia and specifically to the South African context. Choices and decisions for those with dyslexia are often made by others and this research intends to provide those with dyslexia with the opportunity to express their feelings and provide insight into life with dyslexia.

I do not foresee any negative consequences resulting from the questions that I will ask. However, I acknowledge that conversing about past experiences might revive old memories that may or may not be painful to recall. It is however, also providing participants with the opportunity to make their voice heard on an academic platform. Participants will have the choice not to answer certain questions if recall will result in negative emotions for them. I will be mindful and show sensitivity and respect at all times. Should it appear necessary, I will repeat the option that withdrawal from the study can take place and that they must not feel obliged to supply a reason for this. Should this occur I will instantaneously respect this decision. In the event of the services of a psychologist being required I will request the dyslexia association for the assistance of a psychologist who is linked to the organization.

Confidentiality and anonymity will be observed at all times. Participants will remain anonymous. Names will not be recorded anywhere and no one will be able to connect a participant to the answers provided. Interviews and answers will be given a code number or a pseudonym and will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings. I will be the only one who will have access to the data (the audio tapes and your diary/notebook). Responses provided may be reviewed by people responsible for making sure that research is done properly, including the UNISA Research Ethics Review Committee. The data from this study may be used in a research report, journal articles and/or conference proceedings however the names of all participants will remain anonymous. As I am the only researcher involved in this study, there is an absolute guarantee of confidentiality or anonymity, as I will be the only person who will know the pseudonyms that have been used.

Hard copies of answers will be stored by me for a period of five years in a locked filing cabinet and the audio recordings in a locked safe in my gated cluster house, for future research or academic purposes. Electronic information will be stored on a password protected computer. Future use of the stored data will be subjected to further Research Ethics Review and approval

if applicable. Hard copies will be shredded and/or electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact me, Geraldine Hoskins, on …… or email ……. Should you have concerns about the way in which the research has been conducted, you may contact Dr. H. Olivier on ……; email …….. Contact can be made using the mentioned details if you would like to be informed of the final research findings,

Thank you for taking time to read this information sheet and possibly providing me with the contact details of possible participants.

Yours sincerely

Geraldine A. Hoskins- Researcher

Appendix C- Information Letter Requesting Consent for Personal Contact Details to be given to the Researcher

Dear Sir/Madam

My name is GERALDINE HOSKINS and I am a qualified teacher who has taught in a primary school for 19 years. I am doing research towards a PhD (Doctor of Philosophy) at the University of South Africa, under the supervision of Dr. H. Olivier, a Senior Lecturer in the Department of Psychology of Education. My study has received written approval from the Research Ethics Review Committee of the University of South Africa (UNISA). The title of my thesis is:

LIVING WITH THE LABEL OF DYSLEXIA

The criteria are that you must:

- Have a formal diagnosis of dyslexia done by a professional who is qualified to make the diagnosis;
- Be diagnosed whilst in school, in tertiary education or even as adults in the workplace;
- Be between the ages of 18 and 40;
- Be able to communicate in English;

As you comply with the above mentioned criteria, I kindly request you to consent to your contact details being provided to me. Such consent is only for the release of your name and contact details so that I can make contact with you and does not bind you in any way to being a participant in this study.

This study is expected to collect information that could assist others, especially persons in education, in the workplace and in society, to gain an understanding of what it is like to live with the label of dyslexia, using the experiences of those who have been diagnosed with it. Much of what is known has been told by persons who do not have dyslexia, and very little opportunity to describe their experiences, has been given to persons who have been diagnosed with dyslexia. The results of this study will provide a description of what it is like to live with the label of dyslexia and possibly provide others with an understanding of these experiences. I am of the view that adults satisfying the above mentioned criteria, are able to contribute immensely to this study because of their wider and longer life experiences. I am hoping to have

at least 10 participants both male and female. Complying with the ethical requirements of the study, no payments will be made to those who are participating.

Individual and therefore private semi-structured interviews will be conducted which will enable you to describe your experiences of the label. Permission will be sought from each participant for an audio recording to be made of the interviews, to ensure that the interview will be accurately captured. The questions asked will focus on the family, school, teacher and peer experiences before and after diagnosis, reactions to the diagnosis and experiences after diagnosis. Questions will also include tertiary education experiences and workplace experiences (if applicable) as well as social experiences as an adult. Interviews will take approximately 90 minutes at a venue and time that is convenient for the participant. I will provide each participant with a notebook wherein information recalled after the interview can be recorded. Follow-up interviews might be needed to clarify what was discussed in the interview or if further information is needed by me. Participating in this study is voluntary and there is no obligation to consent to participation. If you do decide to take part, you will be given a further information sheet to keep and be asked to sign a written consent form agreeing to participate. Participants are free to withdraw at any time and without giving a reason.

Participation in this study might be for the benefit of providing others with an understanding of the experiences of those who have been diagnosed with dyslexia. This study will also provide participants with the opportunity of making their voices heard regarding what it is like to live with the label of dyslexia. Academic research into what it is like living with the label of dyslexia and views about this label using the voice of those who are diagnosed is limited. The aim of this study is to contribute to the body of knowledge about dyslexia and specifically to the South African context. Choices and decisions for those with dyslexia are often made by others and this research intends to provide those with dyslexia with the opportunity to express their feelings and provide insight into life with dyslexia.

I do not foresee any negative consequences resulting from the questions that I will ask. However, I acknowledge that conversing about past experiences might revive old memories that may or may not be painful to recall. This study is however, providing participants with the opportunity to make their voice heard on an academic platform. Participants will have the choice not to answer certain questions if recall will result in negative emotions for them. I will be mindful and show sensitivity and respect at all times. Should it appear necessary, I will

repeat the option that withdrawal from the study can take place with no obligation to provide a reason for this. Should this occur I will instantaneously respect this decision. In the event of the services of a psychologist being required I will request the assistance of a psychologist.

Confidentiality and anonymity will be observed at all times. Participants will remain anonymous. Names will not be recorded anywhere and no one will be able to connect a participant to the answers provided. Interviews and answers will be given a code number or a pseudonym and will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings. I will be the only one who will have access to the data (the audio tapes and your diary/notebook). Responses provided may be reviewed by people responsible for making sure that research is done properly, including the UNISA Research Ethics Review Committee. The data from this study may be used in a research report, journal articles and/or conference proceedings however the names of all participants will remain anonymous. As I am the only researcher involved in this study, there is an absolute guarantee of confidentiality or anonymity, as I will be the only person who will know the pseudonyms that have been used.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact me, Geraldine Hoskins, on …….. or email ……... Should you have concerns about the way in which the research will be conducted, you may contact Dr. H. Olivier on …..... or email ……...

Thank you for taking time to read this information sheet and for possibly consenting to the release of your name and contact details to me.

Thank you.

Geraldine A. Hoskins- Researcher

Appendix D- Letter of Consent for the Release of Name and Contact Details

I, _____ _____ (name), grant consent to

_____ _____ to release my name and contact details to Geraldine Ann Hoskins for the purpose of this research.

I acknowledge that:

a. This consent is solely for the release of my contact details and that it does not bind me to being a participant in this study;
b. The nature, procedure, potential benefits and anticipated inconvenience of participation will be further explained and discussed with me where after I can decide to consent to being a participant in this study.

Name & Surname (please print) _____

Contact number: _____

Email address: _____

_____ _____
Signature Date

Researcher's Name & Surname (please print) GERALDINE A. HOSKINS

_____ _____
Researcher's signature Date

Appendix E- Information Letter Outlining the Study

Dear …….

My name is GERALDINE HOSKINS and I am a qualified teacher who has taught in a primary school for 19 years. I am doing research towards a PhD (Doctor of Philosophy) at the University of South Africa, under the supervision of Dr. H. Olivier, a Senior Lecturer in the Department of Psychology of Education. My study has received written approval from the Research Ethics Review Committee of the University of South Africa (UNISA). A copy of this approval letter can be obtained from me if you so wish. The title of my thesis is:

LIVING WITH THE LABEL OF DYSLEXIA

The criteria are that you must:

- Have a formal diagnosis of dyslexia done by a professional who is qualified to make the diagnosis;
- Be diagnosed whilst in school, in tertiary education or even as adults in the workplace;
- Be between the ages of 18 and 40;
- Be able to communicate in English;

As you comply with the criteria you are invited to participate in my study. I am of the view that you are able to contribute immensely because of your wider and longer life experiences.

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect information that could assist others, especially persons in education, in the workplace and in society, to gain an understanding of what it is like to live with the label of dyslexia, using the experiences of those who have been diagnosed with it. Much of what is known has been told by persons who do not have dyslexia, and very little opportunity to describe their experiences, has been given to persons who have been diagnosed with dyslexia. The results of this study will provide a description of what it is like to live with the label of dyslexia and possibly provide others with an understanding of these experiences. I am of the view that you as an adult who satisfies the above mentioned criteria, are able to contribute immensely to this study because of your wider and longer life experiences. I am hoping to have at least 10 participants both male and female. Complying with the ethical requirements of the study, no payments will be made to y participating.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

Individual and therefore private semi-structured interviews will be conducted which will enable you to describe your experiences of the label. Permission will be sought from you for an audio recording to be made of the interviews, to ensure that the interview will be accurately captured. The questions asked will focus on the family, school, teacher and peer experiences before and after diagnosis, reactions to the diagnosis and experiences after diagnosis. Questions will also include tertiary education experiences and workplace experiences (if applicable) as well as social experiences as an adult. Interviews will take approximately 90 minutes at a venue and time that is convenient for you. I will provide you with a notebook wherein information recalled after the interview can be recorded. Follow-up interviews might be needed to clarify what was discussed in the interview or if further information is needed by me. Participating in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given a further information sheet to keep and be asked to sign a written consent form agreeing to participate. You are free to withdraw at any time and without giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

Participation in this study might be for the benefit of providing others with an understanding of your experiences as a result of being diagnosed with dyslexia. This study will also provide you with the opportunity of making your voice heard regarding what it is like to live with the label of dyslexia. Academic research into what it is like living with the label of dyslexia and views about this label using the voice of those who are diagnosed is limited. The aim of this study is to contribute to the body of knowledge about dyslexia and specifically to the South African context. Choices and decisions for those with dyslexia are often made by others and this research intends to provide those with dyslexia with the opportunity to express their feelings and provide insight into life with dyslexia.

ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

I do not foresee any negative consequences resulting from the questions that I will ask. However, I acknowledge that conversing about past experiences might revive old memories that may or may not be painful to recall. This study is however, also providing you with the opportunity to make your voice heard on an academic platform. You will have the choice not to answer certain questions if recall will result in negative emotions for you. I will be mindful and show sensitivity and respect at all times. Should it appear necessary, I will repeat the option that withdrawal from the study can take place with no obligation to provide a reason for this.

Should this occur I will instantaneously respect this decision. In the event of the services of a psychologist being required I will request the dyslexia association for the assistance of a psychologist who is linked to the organization.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Confidentiality and anonymity will be observed at all times. You will remain anonymous. Names will not be recorded anywhere and no one will be able to connect you to the answers provided. Interviews and answers will be given a code number or a pseudonym and will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings. I will be the only one who will have access to the data (the audio tapes and your diary/notebook). Responses provided may be reviewed by people responsible for making sure that research is done properly, including the UNISA Research Ethics Review Committee. The data from this study may be used in a research report, journal articles and/or conference proceedings however the names of all participants will remain anonymous. As I am the only researcher involved in this study, there is an absolute guarantee of confidentiality or anonymity, as I will be the only person who will know the pseudonyms that have been used.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact me, Geraldine Hoskins, on …… or email ……. Should you have concerns about the way in which the research will be conducted, you may contact Dr. H. Olivier on ……; email…….

Thank you for taking time to read this information sheet and for possibly participating in this study.

Thank you.

Geraldine A. Hoskins- Researcher

Appendix F- Letter of Consent to Participate

UNISA university of south africa

LIVING WITH THE LABEL OF DYSLEXIA

I, _____ (participant name), confirm that the person asking my consent to take part in this research has provided me with a letter and told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

- I have read (or had explained to me) and understood the study as explained in the information sheet.
- I have had sufficient opportunity to ask questions and am prepared to participate in the study.
- I understand that my participation is voluntary and that I am free to withdraw at any time without penalty.
- I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.
- I agree to the audio recording of the interview and to keeping a note book to record information remembered outside of the interview.
- I have received a signed copy of the informed consent agreement.

Participant Name & Surname (please print) _____

_____ _____

Participant Signature Date

Researcher's Name & Surname (please print) GERALDINE ANN HOSKINS

_____ _____

Researcher's signature Date

Appendix G- Examples of Semi-Structured Interview Questions

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LIVING WITH THE LABEL OF DYSLEXIA

INTERVIEW GUIDE

This interview will focus on recalling experiences prior to diagnosis and after diagnosis. Experiences focused on will relate to family (parents, siblings and relatives), schools, educators, class work, homework, peers, secondary/tertiary education, workplace, experiences and relationships and personal feelings around these issues. Participant's experiences, behaviour, opinions and feelings will be explored.

A. **Background/personal questions asked**:

– tell me about yourself:

Age, education history, family you grew up in, current family, occupation, work history?

B. Concrete questions:

Diagnosis

1. At what age did you realise that you were experiencing the challenges associated with dyslexia?
2. What led to this realisation?
3. At what age were you diagnosed?
4. Was dyslexia explained to you, by whom and in what way did this help you?
5. How did you react to your diagnosis? (Relief, feelings of helplessness.....)
6. Has diagnosis affected you positively or negatively?
7. Do you have concrete examples of how the diagnosis has had an effect on you?
8. Did diagnosis provide relief and improved opportunities or not?
9. What are your views about the word dyslexia being used to describe your learning challenges?

Family, siblings, school and peers

10. Describe your life at home with your parents and siblings before and after diagnosis
11. What memories do you have of school before and after your diagnosis?
12. Which bad school memories stand out for you the most?
13. Which good school memories stand out for you the most?
14. What memories do you have of your family towards your challenges?
15. Which memories stand out for you?
16. Did you need/have extra help at school?
17. Did you work hard at school?
18. How were you treated by your peers?
19. Which peer memories stand out for you?
20. Was your schooling disrupted in any way?
21. At what age did you leave school/education institutions?
22. Did you experience educational policies that assisted you or not- for example attending a special school or remaining in mainstream education?
23. What effect did these policies have on you?

The label

24. What are your feelings about the label?
25. Have you accepted the label and if yes why?
26. Have you told others about your dyslexia and whom?
27. Describe life living with the label of dyslexia.
28. What labels have been used on your in educational institutions attended if any?
29. Has the label influenced your life and how?
30. Discuss the reactions of your family, school, peers, community and or workplace towards your label
31. What labels have been used on you in the work place if any?
32. What are your views about these labels?

Post school

33. Do you have tertiary qualifications and if yes what?
34. What jobs have you held?
35. Describe your tertiary educational experiences?
36. Describe your experiences with dyslexia after leaving school and no longer being a learner but a young adult/adult.
37. What is your social life like?
38. How do you cope with social challenges?
39. What are your hobbies and interests?
40. Do you think that you are a confident person?
41. In what situations are you most confident?
42. What situations do you avoid?
43. Do you get on well with people?

Workplace and relationships

44. Describe your workplace experiences as a person with dyslexia.
45. What challenges do you face at work?
46. How do you cope with work challenges?
47. What is your relationship with others in the workplace?
48. What effect if any does dyslexia have on your adult relationships outside of the workplace?

Goals

49. Has dyslexia affected your self-esteem and how?
50. Try to remember when you were a child living with dyslexia – How do you feel now compared to back then in terms of your ability to achieve and meet your goals?
51. What are your feelings towards achieving your goals?
52. Given all that you have shared, do you feel that the label should be used and why do you feel this way?
53. Last question – what should I have asked you that I did not?
54. Which part of our interview regarding the label should I focus on the most – which experiences with the label are the most profound?